

**Living with cystic fibrosis:**  
**A phenomenological study of children, adolescents, young**  
**adults and their parents**

Submitted by  
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Submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

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## Declaration

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I certify that this dissertation contains no material that has been accepted for the award of any other degree or diploma in any institution, College or University, and that to the best of my knowledge and belief, it contains no material previously published or written by another person except where due reference is made in the text of the dissertation.

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## Abstract

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In response to queries from nurses in an acute paediatric setting, this thesis investigates the experience of children and their parents who live with a chronic, life-threatening and life-limiting disease - cystic fibrosis (CF). Affected families must follow a relentless regime of daily treatment, aware that acute, potentially fatal, exacerbations can occur at any time. What unique challenges and issues for care does this disease present, because of its converse chronicity yet impending life-threatening status?

Anecdotally, nursing colleagues have conveyed their lack of insight into the concerns confronting these children and their parents, while being required to deliver sensitive and informed care. Because nurses generally encounter such families in an acute phase, they have expressed a need to know about their daily experience at home, before the exacerbation of the disease.

Current literature features research with a medical focus, but a paucity of information for those seeking to understand the personal experience of living with CF. Cited studies tend to be situated in large, metropolitan centres, particularly in North America and Britain. That research does not consider an Australian perspective, nor the unique issues that result from isolation and rurality that may be encountered by those who reside in a small island setting.

A phenomenological perspective has been used to frame the study. Data has been drawn from unstructured, conversational style interviews. It includes personal narratives, poetry and drawings that have been contributed by children, adolescents and young adults aged from two to twenty-one years old, plus their parents - eight families in all.



Van Manen's (1990) four existentials are used to consider a lifeworld in which notions of time, body, space and relationship are indelibly altered. Analysis of the participants' contributions has realised eight distinct sub-themes that permeate their experience. From original fright, through ongoing dynamics of fear, fight, flight, form, familiarity and philosophy, they pursue a future that is both threatened and continually redefined.

These sub-themes interplay in the paradox and contradiction of a life correlated with being "all at sea." Of particular magnitude is the parents' struggle in the search for new and accurate bearings - of information, support, and services. Their new reference point is the external reality of confronting life and death on a daily basis, which, although not always conscious, is nonetheless implicit in the execution of each day's rigorous routine. The co-presence of these two dynamics situates those with CF in a *life and death binary* that is the essence of living that life.

Children reveal a growing awareness of, and adaptation to, this life and death dynamic. This is a gradual process in which some participants are still engaged, and about which they speak in comparison with school peers. The young adults have negotiated adolescence attended by extraordinary issues such as death of friends and lung transplantation. They talk freely about their plans for the future that, on the one hand, they once imagined they would never attain, but on the other, is still tentative.

In light of the experience conveyed by participants, implications for nursing education and practice are discussed. Potential areas for further research that have been generated by this study are then considered.

New insight gained from this research project will enable a fresh consideration of those living with CF, as the uncovered truths and impressions provide insight into a lifeworld that may not be as the enquiring nurses had imagined. As a result of enhanced understanding, care can be delivered from an empathetic bearing towards those for whom it is not so much a bothersome routine, but a life and death imperative.

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The children, adolescents, young adults and their parents who shared some of the most private details of their lives, and trusted me to 'handle with care'.

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## Prologue

*"It's a girl! A baby girl!" they exclaimed with delight as the scrawling navy blue form slid between her excited mother's thighs, and lay on the sterile drape. And very beautiful she appeared - well, certainly to them, anyway. Motivated by overwhelming emotion, the ecstatic mother scooped the tiny bundle up into her arms and copious bosom, and embraced for the first time the embodiment of their dreams, the living culmination of nine months of planning, dreaming, hoping and desiring. The mandatory hospital stay fulfilled, they drove home and placed her in her awaiting crib, as one places the final piece in a time-consuming jigsaw puzzle with the satisfied breathing out of completion.*

*"No it only takes a couple of minutes. They do get a bit upset, though," declared the visiting midwife as she lay out the equipment for the routine heel-prick test, and defily grasped the exposed portion that was to be assaulted. One prick and a full bead of the sought-after crimson fluid appeared and dripped into the labelled tube. "Yes, just routine ... for four diseases ... phenylketonuria, galactosaemia, congenital hypothyroidism and cystic fibrosis ... do every baby ... how's the feeding going? ..."* An inordinately large bandaid was applied, the mother placated, goodbyes said, and the nurse drove away to deposit the blood that would go to the laboratory - into the machine - into where dark, naked, horrible truths are spilled unemotionally forth.

*The official envelope lay incongruously stark amidst the lively, handwritten addresses of obvious Christmas cards. Opening that one first to get it out of the way, she pulled out its contents and read the enclosed information - and read it again. That night sleep eluded her, chased away by the incessant pounding, the almost audible chant - "further test ... further tests ... we need to perform ... further tests."*

## A query from practice: question posed

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“And this is the CF unit,” announced my colleague, who was showing me around the tertiary paediatric facility where she is a nurse researcher. I had come to look. “This is our adolescent bay” - a room of six to eight beds looked out on to the busy road, the tall buildings of the city in the distance, and the outside/other world. Individual doona covers declared ownership by those who had long since felt no obligation to submit to hospital issue.

We wandered past another room, a smaller room, one in which there was a hospital cot - the old silver steel frame - not trendy and minimalist - just very, very hospital. But it was empty. The side was down. Where was the child? I lifted my gaze to the window in front of which sat a woman - relationship: mother by implication - holding a very young child. If this was a photograph, ‘Just Diagnosed’ would be the caption, and we’d all say: “Poor thing.” I caught her eye. My guide and I lowered our voices and moved softly along. I had come to look - I had just intruded.

I first encountered cystic fibrosis (CF) while nursing in the paediatric unit of a regional general hospital, located in Tasmania, an island state. Previously it had been one of those diseases that by virtue of acronym nomenclature get filed away and confused with other chronic illnesses illustrated in medical texts, and which are only afforded differentiation when seen in human form.

My preliminary acquaintance with the people who actually live with this disease came via my execution of an academic exercise. The assignment was to present a clinical case study, with the added accent of focusing upon the person as well as the disease. I elected to enquire into the medical condition and lifeworld of an 18-year-old girl with the CF diagnostic label. She was well known to the ward, but conversely, her parents were not.

## **A barrage of questions**

Paper completed and grade awarded, the project had rendered me initial insight. Having cared for this young woman, and others like her, I was au fait with the lengthy dossier of her medication chart, and attuned to a cough the likes of which I had never heard before but could now recognise anywhere. Not new to the field, I was nonetheless naive to the experience, filling the gaps in my knowledge with assumptions.

Subsequently, in the context of my Honours research project (Jessup 1999), I talked with parents whose child had fully recovered from an acute condition that had precipitated an unpremeditated hospital admission. Following these encounters that were committed to narrative, I wondered what might be the stories told by those for whom discharge does not terminate the illness experience. What of those for whom expectation of a cure does not exist at the end of a gruelling, relentless treatment regime?

When the opportunity arose to pursue doctoral research, these initial queries persisted, subtly attended by an acute care emphasis. I tossed my initial leanings of imminently terminal conditions, such as leukaemia, into collegial discussions. I became aware that responses were often another question, and featured a different type of disease - cystic fibrosis. "One mother said to me: 'It's like having a child with cancer, only they don't have a bald head'", Nicola<sup>1</sup> recalled. Prue considered that: "People fail to appreciate the plight of these families", while for Selena other details were obscure: "What about transition of child to adolescent to adult - parents' letting go?" Sally suggested: "I want to know about them at home. We only see them when they're acute. What happens at home to make them acute?" Anna commented: "Graduation - their transition to adulthood?", while Rachel simply said: "What about CF?" So it was in recognition of these voices from the field that my research inquiry has been devised.

Anecdotally, nursing colleagues have conveyed limited understanding of the issues confronting these children and their parents, while being required to deliver sensitive

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<sup>1</sup>To maintain anonymity, pseudonyms have been assigned to those who contributed to this work.

and informed care. Because nurses generally care for such families only when presenting in an acute phase, they were expressing a need to know about the experience of them at home, before the exacerbation of their disease.

My response to my original query was also another set of questions. What is life like for affected children? When and how do they begin to understand that continual medications and hospitalisations may not be so-called normal life, or grasp that they have a disease label, with its attendant issues of life and death?

I considered their parents, whom I had cast as visitors in the CF drama. How do they cope with the initial diagnosis - when they discover they are the parents of a 'monogenetic disorder that presents as a multi-systems disease' (Harrison 1994:1194)? How do they react when they find out that their perfect baby has not come with a guarantee - for whom life is surely, relentlessly going to run out? What is life like for these people? What relational, financial and personal costs are extracted over the years of living with a chronic illness, day after day?

### **A matter of facts**

If I was going to investigate the experience of living with CF, I needed an accurate portrait of the disease around which this life is fashioned. Described as 'an incurable life limiting condition which is the most common inherited lethal condition in most Western countries' (Robinson 2001:237), incidence in Caucasian populations is 1 in 2415 live births (Dodge et al. 1997:493). The Tasmanian incidence of 1 in 1685 live births means it has one of the highest rates in the world (Blest 2000:43).

Most prevalent amongst Caucasians, 1 in 25 carry the CF gene. The disease occurs where both parents have the defective gene, there being a one in four chance that a pregnancy from two carriers will produce a child with CF. There is a one in two chance that this child will be an asymptomatic carrier, and a one in four chance that the child will be neither carrier nor have the disease (Australasian CF Data Register 2000).

CF has evolved from an illness from which a child died in the first months of life (Hutchinson 1972:332), to being dubbed 'now an adult disease' (Elborn 1998:217). Life expectancy 'has advanced well into adult life' (Robinson 2001:237), having increased from an average of eight years in 1970, to 29.5 years in 1998 (Bolyard 2001:39). The predicted median life expectancy for those born in 1990 is estimated to be about 40 years, double that predicted 20 years ago (Elborn et al.1991:881).

Once the result of an array of symptoms, diagnosis is now mostly by screening a newborn baby's blood obtained from a heel prick, a positive finding displaying an elevated reading for immuno-reactive trypsinogen therein. This is confirmed by a sweat test. Other early signs may initiate diagnosis, the commonest being meconium ileus - intestinal obstruction in the newborn - by which up to a quarter of cases are diagnosed (Australasian CF Data Register 2000).

CF is due to mutation of the gene involved in coding the cystic fibrosis transmembrane conductance regulator (CFTR), the protein product facilitating the transport of chloride and sodium ions across the cell membrane (Seeley et al. 1995:84). Characterised by abnormal secretions of the exocrine glands, the effects of CF are evident in the respiratory, gastrointestinal, reproductive and hepatic systems. Sweat glands are also involved, excessive levels of electrolytes in the sweat enabling this to be used as a definitive test.

Abnormally sticky secretions precipitate adverse effects. In the lungs, they block small airways, encouraging infection and necessitating high doses of antibiotics. Daily arduous physiotherapy and nebulization are aimed at minimising not only rates of infection, but also long-term damage. In the digestive system, thick secretions from the pancreas impede enzyme action, leading to maldigestion and malabsorption, requiring the administration of pancreatic enzyme capsules before any meals or snacks. Treatment may delay disease progression and alleviate symptoms, but premature death still occurs (Australasian CF Data Register 2000).

Although the causative gene has been identified, there is no cure. The treatment is, therefore, essentially palliative, and involves affected children and their families in a relentless, rigorous regime often punctuated with lengthy hospital stays and frequent



outpatient visits (Coyne 1997:122). Besides a high energy diet, daily physiotherapy and medications must be adhered to, often enforced upon a child who may not be feeling unwell, and may not grasp the long-term prophylactic implications thereof.

Lung transplantation is a reality in the end stages of the disease, although it is a palliative, rather than curative, procedure. It requires well-timed referral to a transplant centre when the clinical course predicts survival that is slightly longer than the anticipated waiting time for donor organs, which could be from six months up to two years (Yankaskas et al. 1998:225).

Genetic research into both treatment and cure has seen CF mentioned along with cutting edge experimentation (King 2004:7). Gene therapy, whereby a carrier molecule, or vector, is used to transfer new DNA to disease-affected cells, is still being perfected (Staff 2001:485).

### **Gathering evidence**

Being thus well versed regarding the aetiology and epidemiology of CF only exacerbated the deficit in my understanding of living the life. I saw the potential for a study to complement current medical insights, thereby helping to build a more complete picture of the experience, particularly for those for whom care is moderated by their location in a quasi-rural island state. By giving voice to the circumstances, concerns and issues confronting these families, I aim to facilitate reflection and understanding in nursing practice that will initiate the informed planning and provision of new approaches to care.

Why is this knowledge important? I assessed the process thus far. I had the nurses' request. Lack of knowledge of life with CF also extended to people of no medical persuasion, although interested enquirers into my research project would often respond with an anecdotal description of a CF scenario across which they had come. So it was that I built up a picture that included an adolescent girl who had died in the mid 1990's. A friend visiting from interstate painted an affectionate portrait of a young man in her son's class, her description of his sporting achievements tainted with a sadness that culminated in the punch line that he had died of CF. Another

raconteur immediately recalled a woman who had “lost three as babies and has one living.”

I also remembered several nurses' exasperation at one particular child - Brittany - and especially her father. Depicted as one standing guard and in a sense, overseeing the mode of care even when he was not in the ward, he was not given very positive press at change of shift handovers. It was expressed that he overprotected his daughter as a “precious princess.” Such responses concerned me, as I had a sense that we nurses were intercepting their lives at one specific juncture only. What might be an alternative understanding on the part of nurses? Why did Brittany's father respond as he did? What scenes were played out when life was not enacted in the hospital setting? What stories would such people tell? Not only did those caring for them need to hear, but there was also a more subtle potential on the part of those living with CF. When gathering people's stories as an Honours researcher, I had witnessed first hand that often for them there were ‘positive outcomes of being given the opportunity to tell their story to someone who will listen’ (Gibson 1999:311).

There is a need to understand the experience of those living - and dying - with CF, a somewhat unique disease because of its converse chronicity yet impending life-threatening status. I was fascinated with the copious medical research I had read, with titles such as: ‘Cystic fibrosis presenting as a massive hepatomegaly’ (Arumugam et al. 1999:731). But what about the person attached? Other titles like: ‘Detection of modifier loci influencing the lung phenotype of cystic fibrosis knockout mice’ (Haston et al. 2002:605) equally intrigued me. Such research is vital, especially to those living with CF, who I imagined to be hoping for a breakthrough.

Chronic illness is increasing dramatically in the Western world, making it an important research focus for health care disciplines (Gjengedal et al. 2003:149).

I had read that: ‘Nurse researchers are in a good position to further develop a sound body of knowledge about the experience of living with a chronic illness’ (Admi 1995: 499). By utilising integrative perspectives and qualitative methodology, further insight could be added to the ‘current initial state of knowledge in this field’ (p.499).

'Parents of children with a chronic illness have found that hospital staff underestimated the magnitude of emotional problems experienced by parents', writes Coyne (1997:126). If asked, what would parents like Brittany's add to this? Coyne concludes that: 'Each family situation is unique and each family interprets and responds to illness in its own way.' These people apparently 'often know more about the disease, the treatment and any new research relating to it, than the nurses who care for them.' (Tippl 1995:127). But what did nurses know about *them*, I wondered?

It was during this formative stage that I had a very timely encounter:

*It was a familiar scene, really - the meandering towards the ward door, the nurse supplying final information and instructions; and the interplay of pleasantries which signify the terminating of an encounter. Helen waved goodbye to Bob, and then turned her farewell gestures towards his younger siblings, who were vying for attention. Then they were gone - to another world, to their world. The scene was tainted with a familiarity not common to all hospital discharges. Definitely au revoir, not goodbye.*

*Bob is a young man with CF, whose details at handover that morning had been simply, 'Nebs, meds, puffers - physio and enzymes' - the CF chant. Now he and his family had gone out the ward doors, down the corridor towards the lift, which carried them away. If asked, we could picture them at the front doors, exiting to another world - another life, really - one we could only grasp with the imaginative rather than natural eye. That image would be deciphered by correlation with past experiences we have filed away. With the addition of rugged supposition, it could go so horribly astray from what might be the day to day life world of those whose diagnosis defines not so much an error in genetics, but a particular life script, an understanding of which can render us sensitive in our attention to their care.*

*We can recite the routine, but how do we grasp the experience? Farewelling them, we wave them off as they leave our visual field - to far horizons. Nurses 'see'. Thus I was somewhat bemused when these clinicians had requested: "What about CF?" - Did they not know? "We don't see them at home". - Had they not been acquainted with these families over painstaking years, as declared by the ward photo album? Yet*

*they perceived their view to cease at the ward door - this far and no further* (Jessup 2001, unpublished journal).

I reconsidered this encounter in light of the queries practice colleagues had raised. As a result, my research question was consolidated and my focus defined. I would ask: “What is the experience of living with cystic fibrosis?”

### **A narrative bent**

The ensuing chapters will describe the process followed, and trail taken, by which I have sought an answer to my query. This is the account of a research project, and also the story of my journey as researcher. To gather data, I have crossed personal boundaries and entered the participants’ world. How was I to present this context to you, the reader? By using the phenomenological lens, I have focused on ‘the nature of the lived experience of illness ... as it is expressed through a story, poem, painting’ (Darbyshire 1994:858), and in this instance, drawing. I have adopted a narrative style in which I am both researcher and narrator.

My descriptive prose is heightened by the use of metaphor, described by Czechmeister (1994:1232) as ‘enhancing meaning’ and ‘basic to creative thought’. There are instances in my description of the research process, and in my interrogation of the participants’ contributions, where metaphor has aided my derivation of meaning from illustrations that may otherwise have been elusive. This has been a separate process from that in which participants have drawn upon metaphor to inform their experience, a theme that will be a topic of subsequent discussion.

What follows is a story. I have woven mine with that of the participants, aware that ‘the power of narrative is that it moves us not only to think and evaluate, but to live in a special place smelling the smells and feeling the full impact of human experience’ (Vezeau 1994:169).

## **A synopsis of the thesis**

**Current publications: disclosing the gap** establishes not only that which previous researchers have written, but highlights a void that invites exploration, to complement and extend existing knowledge.

**A phenomenological perspective: passé or prophetic?** considers how I framed my inquiry. It considers contemporary phenomenology in light of its foundational tenets, providing justification for its efficacy and inherent suitability for the research question.

**Preliminary processes** delineates the *modus operandi* that has structured the research procedure, from meeting participants within ethical guidelines, to the appropriate handling of their contributions, including the rigour that such a method affords.

**Prose, poetry and pictures: data disclosed** is the means by which you, the reader, co-construct the unique lifeworld of those living with CF. The culmination of a myriad of conversations and interactions with children and parents, this part of the work presents their response to my asking them to tell their story. This is a collection of narratives, poems and drawings that, together with my description, reveal the experience under consideration.

Perspectives of CF are drawn from participants' experience that spans two decades, involving nine children. The youngest is two years old while the oldest is twenty-one, with those in between spanning childhood, adolescence and young adulthood. Thirteen parents contributed to the study, some electing to interview together, others separately. Due to particular circumstances in several families, one parent participated.

**A periscopic perspective: data discussed** is the synthesis of common themes that have become apparent during my initial interactions with participants, and consolidated during my subsequent emersion in the data. Fright, fear, fight, flight, familiarity, form, future and philosophy - the interplay of these themes in the lives of the participants is discussed.

**A panoramic perspective: phenomenon portrayed** conveys the fine tuning by which the phenomenon appears, and is, perhaps, the heart of the work. Having been melded by thematic threads, the narratives and other creative expressions are further condensed until the essence of living with CF is revealed.

**Epilogue: putting possibilities into practice** puts forward proposals not only for further investigation, but also for nursing education and, particularly, practice, from whence the original query is derived. Thus the work, but by no means the understanding of this experience, is brought to conclusion, moderated by the limitations of human research and a lifeworld that is dynamic and exceptional.

## Current publications: disclosing the gap

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‘Woe to that child which when kissed on the forehead tastes salty. He is bewitched and soon must die.’ This adage from European folklore is variously dubbed ‘early’ or ‘ancient’ in contemporary sources (Merullo:2002; Sellman:2002). While it may initially appear somewhat quaint, it is a statement of the then existing knowledge of the diagnosis and prognosis of CF. That my nursing colleagues have asked: “What about CF?” made me wonder whether current literature has progressed beyond a similar objective presentation of the status quo at the exclusion of the experience of both the children and their families. These nurses’ request: “We want to know about them at home” suggests that there is a lack of knowledge of this particular lifeworld beyond the ward setting. My quest to confirm this void has lead me up hills of scientific breakthrough, down dales of improved treatment regimes, and through valleys of premature mortality, only to emerge still wondering: “What is the experience of living with CF?”

Rereading the old adage with a contemporary understanding of not only the disease, but also its prevalence, one can but imagine a bereaved mother’s tentative kiss of subsequent newborns, oblivious to a latent world wherein a diagnostic kiss has given way to immunotrypsinogen testing and the prognostic ‘soon must die’ has been absorbed into baseline annual mortality rates. Yet was that mother’s trauma at diagnosis, for example, any different from a woman who is our contemporary? While there may be conjecture as to what living with CF is like, with some families having been given the opportunity to enumerate their experience in questionnaire form in other studies, does the abundance of current literature adequately explore such issues? I believe my clinical colleagues have been attuned to the current discourse around CF but have not heard a particular voice - one they know should be amplified - that of those who live with this disease. ‘Despite numerous anecdotal and research studies that were conducted over the last decade to examine psychosocial adaptation of young people with CF ...,’ considers Admi (1995:501), ‘little is known and understood

about this phenomenon.' What were the existing studies? Was there need for another? A search of the current literature would reveal with what sort of profile CF is presented. What engendered its movement from anonymous scourge to documented disease? How has it arrived at its contemporary pneumocentric stance, where papers considering quality of life are anchored to 'forced expiratory volume in one second (FEV1)' (Goldbeck et al. 2003:42; de Jong et al. 1997:95)?

### **1938 - 'As yet too little is known'**

Early writings include a paediatrician's inconclusive findings presented to a medical research forum in which she describes an array of elusive symptoms of both a nutritional and respiratory kind. Andersen's (1938) contribution resembles that of a detective, calculatedly considering the available clues. For the present day reader, however, her work is not unlike reading a mystery with the foreknowledge of 'whodunit'. Confronted with a set of nebulous symptoms whose nucleus appeared to be that of the pancreas, she suggests the disease should be considered a new entity (p.396). The post mortem examination of 1000 wasted little corpses, 605 pancreases from which sometimes demonstrated a slight grating sound as the knife passed through calcified concretions (p.359), left them 'puzzled' and declaring of this disease 'as yet, too little is known.'

What of the parents of those deceased children, who left behind at the hospital yet another sibling whose lifespan had been measured in mere weeks or months?

Andersen (1938:397) offers them only one definitive - it may be congenital. She concludes that 'the infant refuses to survive' (p.396) - as if in some wilful attempt to be rid of the encumbrance of life. Little did the assembled researchers realise that they were staring at 'the most common life threatening autosomal recessive disorder in Caucasians' (Dodge et al. 1997:493). Anderson's (1938) work is a stark contrast with current papers, which with minimal exception, begin with a statement to that effect, followed by a succinct paragraph enunciating the now well-known aetiology of CF.

It was while Andersen and her colleagues were making pathological connections between symptoms that Fanconi, a Swiss paediatrician with a flair for recognising uncommon clinical patterns as significant disease entities, was tying those symptoms



together into a neat syndrome. His fame is perpetuated by conferring his name not on CF but on Fanconi's anaemia (Stevens & Meyer 2002:902).

### **The research trail**

Afforded nomenclature, CF formally entered the medical arena, and a collection of symptoms became a disease entity. Inquiry could now be focused, ending the uncertainty that had dogged both families and physicians alike. In a case of know the enemy in order to defeat it, a notion of quest pervades the literature on CF - a search for the holy grail of both a causative and curative kind. Corey (2001:743) writes: 'The mantra of improving survival permeates every paper related to prognosis or treatment for CF in the past two decades.' Such an orientation pervades, and while not negating this imperative - indeed, had I a child with this condition, I would be glad that, to continue the crusade analogy, someone is fighting on my behalf. However, it is written *around* them, and *for* them, the process lacking the reciprocity of permitting *them* to effectively contribute. The procedure now documented is not the post mortem knife grating through preserved pancreases, but the surgeon's scalpel, exhuming cadaveric lungs.

Thus has been instigated the trail of scientific research which has culminated in the contemporary stock. It forms a mountain of hope to which families can look. But where have they entered the literature?

### **1960's - web of silence**

It was during the 1960's that snippets of information considering families with CF began to filter into the journals (Burton 1975:10). One of the first is the work of an American social worker who highlights the burden the disease imparts, not only financial but importantly relational, concluding with the description of the 'web of silence' in which affected children are locked, believing themselves to be a burden on their family (Turk 1964:67).

But where has CF debuted in nursing literature? By way of exemplification, a trio of studies highlights the experience of CF in each of the last three decades of the twentieth century. Illuminating the concurrent advancement of understanding with

medical progress, each reflects experience in the light of the existing medical knowledge, life expectancy and favoured methods of nursing research.

### **1970's - living and coping**

In a British study published in 1975, Burton documents the slow spread of the knowledge of CF, since its definition in 1939, when children died undiagnosed with the interim label of 'delicate' or 'chesty', and without the panacea of antibiotics. She describes increased survival rates - to at least ten years old - as freeing caring personnel from needing to concentrate solely on the reversal of symptoms (p.2). Now the social and psychological wellbeing of affected children and families could be considered (p.7) in a new era in which notions of surviving gave way to those of living and coping (p.3). This study, though obviously dated, provides a valuable insight into the context of CF at the time, when diagnosis was the result of meconium ileus or lengthy uncertainty and unwarranted criticism of parental care amidst an exacerbating array of symptoms - or the loss of an older sibling or two.

While scientific research might have moved on, causing the evolution of new issues relating to CF, in a sense, do subsequent families grapple with the same concerns of living and coping with a chronic, life-threatening disease?

### **1980's - further questions**

A Scottish study undertaken in the 1980's by Whyte (1989) is a five-year longitudinal ethnographic description of living with CF. This study sought to provide insight into the experience of families caring for a child with CF, and their nursing support, at a time when paediatric philosophy was expanding its focus from the ill child to the inclusion of the whole family as unit of care (Cleary et al. 1986; Miles 1986; Turner 1984). In Britain, this occurred in the context of evolving paediatric community nursing and subsequent home-based care. Although, were these practitioners, asks Whyte (1989:342), concentrating on illness rather than total family care?

Incorporating King's theory of nursing and the notion of the family as a system, Whyte (1989) attempts to contribute further to the development of nursing theory. Set against a backdrop of those with CF living at least until 20 years old, the anticipated loss of a child is still a focus of the literature review (p.12). It is somewhat dated,

however, stating the current scientific *status quo* at that time to be that 'the basic protein defect has been identified' (Whyte 1989:18), enabling more accurate diagnosis. Its projected hopes, which have now been realised, include the devising of better screening tests for carriers, and 'even gene therapy.' Her recommendations for further research include a phenomenological study as a way of informing 'a very personal and sensitive area of experience which should be understood in the context of holistic nursing' (p.358).

### **1990's - a step in the right direction**

A descriptive exploratory study in the early 1990's (Admi 1993) sought to gain insight into the experience of growing up with a chronic illness from the insider's perspective. Utilising CF as an example, it focuses on adolescents, who because of increasing survival rates, were living long enough to warrant exploration of their journey to adulthood with a disease that had 'recently ... become one of the major health problems of adolescence and young adulthood' (p.1).

Acknowledging the abundance of scientific literature on psychosocial adjustment to CF, Admi (1993:2) points out that it is generally medically orientated, quantitative or cross-sectional in design, with a slant towards seeking deviance. She carves a niche for her project by citing the absence of qualitative nursing studies which 'capture the complex experience and meaning of living with CF'. Admi employs a retrospective, longitudinal, life history method, from which to generate grounded theory. Aided in this pursuit by Mandelbaum's (1973) theoretical framework, she constructs an 'ordinary' model, deducing that, in the lives of her participants anyway, 'their disease was of little centrality and relevance to their psycho-social lives and became central only during defined episodes, such as hospitalisation or the death of a friend with CF' (Admi 1995:viii). Admi (1995:490) describes those participants' handling of disease-related information as the 'who, how and when' of telling, a process which she deduces changes over time. This work concludes with the recommendation that:

Nurse researchers are in a good position to further develop a sound body of knowledge about the experience of living with a chronic illness by relying on integrative perspectives and using qualitative methodology, which is compatible with the current initial state of knowledge in this field (p.499).

She nominates her study as being: 'one step in this direction' (Admi 1995:499), and I concur, deciding that I will take one further.

## **A new century - a new look**

### **A fine pedigree**

Main players in the literature are an array of scientists enthused not only with the quest to alleviate CF suffering via panacea and cure, but also by the elusive research dollar and personal recognition derived from a scientific milieu populated with laboratory mice (Dickinson et al. 2002:243; Haston et al. 2002:605). Where is the voice of those for whom such technology purports to exist, and in whose ultimate interest such exploratory research is undertaken? Stockdale (1999:579) presents them swallowed up as bit players in a larger production, subsumed in a grander plot dominated by researchers and commercial enterprise rather than altruism.

Considering the tactics of the American Cystic Fibrosis Foundation to be heavy-handed, Stockdale considers that fundraising, which promotes scientists verging upon a 'cure' for this 'child-killer' disease, forms an emotive smokescreen for a disease which is no longer just a paediatric one, and for which any cure continues to be elusive.

### **Cracking the code**

In this climate of 'geneticization', wherein genetic explanations dominate in medical and social discourse (Hedgecoe 2003:50), labels such as 'bad genes' (Campbell 2003:193) are bandied about. In a case of Punnett squares versus lived experience, theories of Mendelian inheritance frame risk in static, objective terms, abstracting it from the messy subjectiveness of human relationships (Cox & McKellin 1999:624). Amidst a want of contrasting qualitative reporting is the voice of one young woman with CF who has dubbed herself 'genetically programmed to self destruct' (Hillyard 2001:S20).

Genetic technology has precipitated discrimination in areas such as life insurance, where a British survey reported CF carriers being treated as if they had the disease, with 5% of respondents being refused coverage and 2% being charged higher

premiums (Low et al. 1998:1634). The authors conclude this to be the result of the inappropriate interpretation of genetic information. Issues regarding privacy of stored data take on new meaning when a datum is one's DNA, and potentially a factor not only for insurance but also employment decisions (Nelkin & Andrews 1999:703).

Population-based screening for CF has been found to exert a negative effect on identified carriers, who perceive their current health to be poor, despite being told their carrier status does not disadvantage their physical condition (Axworthy et al. 1996:1443). A covert discourse around those found to carry deleterious genes is that they are not poor victims but are charged with a notion of social responsibility (Hallowell 1999:597). Some papers describe an almost Orwellian ridding the family of undesirable genes when the benign study of pedigree releases the potential for labelling 'normality' and 'abnormality' in the quest for 'desirable' (Bennett 2000:248). This begs the question: 'how many tests will an unborn child have to pass' (Silva 2002:556)? In light of current research and technology, what would parents of CF children contribute to such scientific debate?

### **Advance screening**

While antenatal screening for CF has resulted in a reduction of the incidence of the disease in Edinburgh, the only city in the United Kingdom with an established programme (Cunningham & Marshall 1998:345), a corresponding perceived assumption of termination of pregnancy evoking parental anxiety has been reported. A Nottingham study considered parents who already had a child with CF or Down's Syndrome. Of the cohort, a third of the couples who had a child with CF believed they would terminate an affected foetus. Several others said they would not consider prenatal testing or termination of the pregnancy of a subsequent foetus, seeing it as devaluing the life of their first child (Polnay et al. 2002:285).

'What is a life worth living (Chapman 2002:195)?' Has quality of life lead to quality control? Parents of an affected child will be given positive information emphasising medical advances, while prospective parents will be negatively informed, with an inference of undesirability in producing such a baby (Lippman & Wilfond 1992:936).

Chapman (2002:205) concludes that the voices of people living with genetic conditions should form part of wider bioethical debates that arise from advances in genetic technology. These voices may be picked up effectively via a qualitative methodology.

### **Diagnosis: neonatal ‘screaming’**

For those families in previous decades whose child either died undiagnosed or who stumbled upon a clinical diagnosis, the simple procedure of neonatal screening via the immunotrypsinogen test would not be open to efficacy debate. However, it is not routine in many countries. Australia and New Zealand have national screening (Baroni et al. 1997:143), New South Wales having begun in 1981 (Dudding et al. 2000:F124).

American debate over early diagnosis altering the course of CF has resulted in proponents calling for the introduction of mass screening (Doull et al. 2001; Farrell et al. 2001), while detractors decry it as an extra cost with no perceived clinical benefit, unless a sibling is already affected (Macready 1997:1299). While screening has been widely advocated in the United Kingdom by clinicians and groups such as the Cystic Fibrosis Trust, about 20% of babies are currently tested, the United Kingdom National Screening Committee (2002) nominating it ‘not a fool-proof process’. Dodge (1998b:411), however, suggests that parental shock at diagnosis may be mitigated by knowing that it has been made early, alleviating the anger and mistrust that some have felt when diagnosis has been delayed, with potentially preventable lung damage avoided. Perhaps it is time for parents to have their say.

### **A costly life**

As one seeking the experience of those living with CF, I approached the concept of cost in the literature assuming it would have a personal slant, only to find that the prevalent considerations of cost are of a pragmatic nature. ‘What is cost effectiveness in cystic fibrosis?’ asks Conway (1998:1). He deduces it to be a varying concept, with patients and their parents believing to be cost effective any treatment that makes them feel better, no matter how high the price may be. Those administrators entrusted with budgetary restraints, however, are likely to judge cost effectiveness on resultant reduced need for other medications and hospitalisation. On the other hand, clinicians

deem cost effective any treatment rendering improvement to the patient's condition and quality and quantity of life, with the hope that someone will be willing to fund it.

In some instances, finance is not forthcoming, with CF patients being denied medication, for example, because of its cost. The notion of expenditure is one of which they, and their parents, do not want to be continually reminded, being only too aware that the condition is an expensive one to treat (Walters 2002:32). Cost is not static, but rather rises with age, doubling in the first eighteen years of the patient's life. There is a direct correlation with chronic *Pseudomonas aeruginosa* infection and lung function (Baumann et al. 2003:84). Provision of expensive treatment is also tainted by the fact that poor adherence to it exacerbates not only fiscal cost but also that of a personal nature, in health outcomes (Wald et al. 1993:1308). Such discussion begs the consideration of what contribution those who live with CF would make to the debate.

But this is not the only financing of their care that is calculated to be too great. *Broker World*, (Goldstone 1998:78) for example, focuses on the 'insurable' rather than the 'incurable', despite increased longevity. Incurable those with CF might be, but insurable they are not.

Financial efficacy forms a substantial quotient in the portrayal of screening - both antenatally and prenatally. British antenatal quotes of 'cost per couple about fifteen pounds' (Wald et al. 1993:1308) are more reminiscent of catering projections rather than a means whereby '200 of the 300 cystic fibrosis pregnancies each year could be detected'. This would be at an annual cost of ten million pounds if introduced nationally. Screening for CF carrier status, writes Braekeleer (1994:173), should not be assessed for cost benefit, but rather personal benefit.

While main players in the varied fields of medical care are each entrusted with their particular calculation of cost, those with CF and their families are encumbered with them all, plus the common denominator of inestimable personal cost. How is this considered in the literature?

### **All in the family**

Current cited studies are notably situated in large, metropolitan areas - particularly American and British settings (Lai et al. 1999). Such research does not consider an Australian perspective. Nor does it address the unique issues of isolation and rurality which may be encountered by those who live in an island setting, and must negotiate access to care, temporary dislocation to larger centres, and other complications confronting those living in a small community.

The personal, individual and long-term experience of such families has not been studied in a form which can potentially influence either their support or care (Hill et al. 1997:517). Predominant research approaches in the literature are quantitative in design. Qualitative studies tend to be in an ethnographic or case study format (Christian et al. 1999), or qualitative research documented in the context of outmoded methods of diagnosis and care, such as Burton's (1975) and Whyte's (1989) studies. What is the experience of families in light of current modes of treatment and care; where increased potential for attaining adulthood (FitzSimmons 1993:1) is accompanied by extraordinary life decisions such as lung transplantation?

Research has focused on adolescents (Peggy et al. 2001). Inclusion of the experience of both children (Nespor 1998:369) and young adults could bring a broader knowledge of patients' experience of illness across their limited lifespan.

### **Seen but not heard**

Children are well represented in the literature, but mostly type-cast into a passive yet central role as those *for* whom diagnosis has been achieved, *upon* whom certain medication trials have produced a result (Davies et al. 1997:243), *about* whom family dynamics must adjust, services are designed (Darbyshire et al. 2001:190), and siblings take an outer place (Bluebond-Langer 1996:262). At first read, they appear well-catered for, but mostly represented by the third person pronoun. This begs the question: 'how are they experiencing this disease called CF - what is life like for them?'

A breath of fresh air is the strand of study which seeks to debunk the 'perceived passivity of the voice of children in health care and research', acknowledging that



children are capable of interpreting their world (Sartain et al. 2000:913). A reluctance to engage with children in research may come from their views being considered irrational or invalid, only gaining legitimacy by adult explanation and validation (Darbyshire et al. 2001:190). Overseas studies have emerged in which children with chronic illnesses including CF have talked and drawn about their experience, but in settings such as the North-east of England (Sartain et al. 2000:920).

The expectations of children with CF has certainly progressed beyond those considered in a 1970's study in Ohio (Tropauer et al. 1970:424) that examined psychological aspects of care, in which one little girl's response when asked about her future ambitions was 'to be come a teenager'.

While there is an ample supply of literature dealing generically with children and chronic illness (Chernoff et al. 2002; Garwick et al. 1998; Gibson 1999; Kieckhefer & Trahms 2000; Kliebenstein & Broome 2000; Knafl & Gilliss 2002; Kyngas 2000; Sartain et al. 2000; Sawin et al. 2003), those with CF seem swallowed up within it. Conversely, they are harnessed to a disease buddy, such as diabetes mellitus; a disease that is certainly chronic, but devoid of as many potential hospitalisations, as rigorous therapy, and a life and death status (Lowes & Lyne 2000; Gjengedal et al. 2003). Children - and I would add diseases - cannot be treated as an homogenous group (Sartain et al. 2000:914).

Consideration is given to psychological impact in children with CF. A North Carolina study (Thompson 1998) examining psychological adjustment and cognitive adaptation processes concludes, not surprisingly, that the daily illness demands associated with CF may illicit oppositional behaviour, with a resultant impact upon compliance and health maintenance (p.127).

### **Schooldays**

Noting the lack of documentation of school experience for children with CF, particularly in the United Kingdom, Zoritch et al. (1996) administered a questionnaire to the teachers of 41 children in the Nottingham and Sheffield districts. Restrictions at school were found to be not governed by the child's clinical status, but rather imposed and moderated by parents' perceptions. Teachers' knowledge of CF is

generally poor, with over half expressing a wish for more information, particularly regarding treatment and symptoms. The investigators conclude that the children studied display a remarkable resilience to the stressors that CF could potentially impose on their school life.

A controversial issue is that of medication at school. While parents may feel empowered to insist that teachers take responsibility for childhood illness during school hours, teachers' professed anxiety about accepting such liability reflects their focus on health promotion rather than providing 'acute medical care'. As parents hold the prime responsibility for their children's welfare, accountability for medications becomes a point of negotiation rather than demand (Bannon & Ross 1998:1591).

### **Adolescent awakenings**

As I perused the publications, I was attuned to seeing, as it were, adolescents' side of the story. How do they negotiate the acknowledged rocky road of pubescence, encumbered with a disease that strikes at the very issues that are paramount in the minds of adolescents? The passage from child to adult is an embodied experience. What impact does CF have upon the transition to adulthood?

The child with CF is now at a stage where being shorter in height than average (Beker et al. 2001:438), under-endowed with the tissues that make for supposed attractiveness because of disease process and the resultant late onset of puberty (Boas et al. 1998:573) - that is, muscles in boys and slim yet curvaceous lines in girls - may strike at the core of self esteem. A project (Truby & Paxton 2001) from the Royal Children's Hospital in Melbourne considering body image and dieting behaviour in CF, interviewed children aged from seven to twelve years old. It suggests that, in this age group, those with CF had similar body esteem and general self-esteem as those in a control group, but were more likely to perceive their body size as larger than it is. The discussion suggests, however, that as they get older, children with CF become aware that they are 'in a different position' from their peers. Negotiating such awakenings with a positive view of themselves and their body is likely to reduce subsequent adverse psychological effects. Of particular concern was that children with CF are thinner than average, thus fitting the prevailing body size, and so may not be motivated to comply with their required high-energy diet.

A study considering eating disorders and psychopathology in patients with CF utilising structured psychiatric interviews and rating scales, could demonstrate no elevated rates of either (Raymond et al. 2000). Those with CF, however, not only took longer to eat than controls, but also engaged in more intense interaction with their parents about the process of eating.

Notions of normalisation are woven throughout the discussion of those living with CF and their families; and there is probably no life stage when this dynamic is more manifest than in adolescence, mostly moderated by the peer group to which the young person seeks to belong (Willis et al. 2001; Gjengedal et al. 2003).

The consideration of living with CF as a gendered experience is the subject of Australian research from Latrobe University (Willis et al. 2001). For adolescents, not being considered different can take precedence over compliance with medical regimes. While they may comprehend the future implications of non-compliance, for the present time, these are of lesser importance. To understand this, state the authors, the adolescent needs to be considered as embodied subjectivity rather than a candidate for scientific inquiry and intervention. Generally, the regime for those with CF is intense, on the one hand, and yet adverse effects from not adhering to it are not immediately felt. Attempts to achieve the perceived socially desirable body image can impact upon morbidity and indeed mortality (p.1165).

This study (Willis et al. 2001:1172) suggests that while young females experience greater concern about their health than their male counterparts, they are less physically active, eat less, and have lower health goals and a greater morbidity than males. They are also less likely to find any sense of positiveness in their daily living with CF, resulting, these researchers would suggest, from the social practice of femininity entailing passivity and powerlessness. A pervading need to be attractive rather than active adversely affects morbidity.

A study in North Carolina examined risky behaviour incorporating teens with CF. These teenagers displayed fewer risky, and more injury-prevention, behaviours than peers their own age and race (Britto et al. 1998:250).

A further Australian contribution to the adolescent research studies is a psychology-driven one from the Flinders University (Graetz et al. 2000). This project, executed in the mid 1990's, investigates perceived supportive and non-supportive behaviours of the family and friends towards those with CF. Utilising a modified Chronic Disease Support Interview, assessment with a Youth Self Report Form, and repeated-measures analyses of variance, it concludes that family members provide more tangible support - such as with treatment tasks - while friends proffer companionship.

Another issue arising from this study is the notion of disclosure of the adolescent's disease status to peers, a subject of further studies (Admi 1995; Graetz et al. 2000; Lowton 2004). It concludes that while parents are considered a support, this relationship can be tainted with the natural adolescent view of their parents as 'nagging', especially regarding treatment compliance. As the young person negotiates the normal process of separation from parents in their maturation to projected adulthood, however, those with CF are less likely to emancipate by moving away from home or finding a job (Raymond et al. 2000:362).

Nurses who care for adolescents are the subject of an Honours in Nursing project from Monash University. Tippl (1995) considers the nurse-patient relationship in this context of the 'chronic/terminal dichotomy', wherein the adolescent is doubly vulnerable because of developmental needs plus the dependency inflicted by a terminal illness. She also acknowledges that these young people and their families are empowered by the fact that they have contended with disease and hospitals for most of their lives, often knowing more about treatment and the latest research than the nurses who care for them.

### **Sexuality matters**

Adolescence is a time of sexual awakening. For those with CF, this is once again complicated by the juxta-positioning of normality with abnormality, as they start to consider procreational issues. The few available studies show that while adolescent males with CF have a 'strikingly poor understanding' of the effect of the disease on their reproductive health, females fare even worse, lacking even the most basic information about the effects of CF on issues such as their fertility (Sawyer 1996:1095). Sawyer suggests that young people deserve more extensive

research about their sexual and reproductive needs. She describes various gaps in understanding, leading to several questions. What is the best time to discuss reproductive health and what should such discussions contain? At what age will young men want to know about their probable infertility? When are they ready to contemplate reproductive technologies? And what of telling a future life partner about yet another negative attribute of this life-choice impacting disease?

Surveyed Australian health workers consider 13.8 years as the most appropriate age to discuss infertility with young males, despite the fact that most did so at 15.2 years; citing embarrassment, insufficient time and training, or simply not the 'right time' (Sawyer et al. 2001:36). A Harvard Medical School inquiry of young men found that 90% of their respondents reported no major distress initially upon learning they were infertile, albeit that the notion actually attained greater significance over time (Sawyer et al. 1998:293). By contrast, Scottish postal questionnaire compliers suffered shock and bewilderment upon hearing of their sterility, such news not always coming from a health professional (Fair et al. 2000:672).

Equally complex are such issues for young women, who are considered to 'fare even worse' when it comes to availability of information on fertility issues (Sawyer 1996:1095). Even in girls with good clinical status, menarche is delayed (Edenborough 2001:649). The possibility of achieving pregnancy, once considered remote because of insufficient study numbers (Sawyer 1996:1095), is now being reassessed in the medical literature, along with the risks it poses to a body which may be struggling to breathe and sustain life for one. From the Adult Cystic Fibrosis Unit in Sheffield comes the comment that although some fear the effect of CF on themselves and their child via inheritance, healthy women with CF can anticipate a normal pregnancy (Edenborough 2002:691). Canadian results are similar, concluding good maternal and foetal outcomes (Gilljam et al. 2000:85), these being, I would suggest, somewhat short-term consequences. Documented along with this are the stark issues of the possibility of the baby having CF - and all that entails. The reality, at this stage anyway, is that the woman will die in her third or fourth decade of life, generating questions of care of offspring (Edenborough 2002; Walling 2002), issues which are also now applicable to males in this era of assisted reproductive techniques (Stuhrmann & Dork 2000:71).

Like their male counterparts, girls with CF and their mothers, who completed questionnaires at the Royal Children's Hospital in Melbourne, displayed unmet needs regarding their sexual health information, many having erroneous notions of infertility and unawareness of pregnancy risks. While the girls regarded their mothers as their source of facts, these women are not always appropriately informed. The recommendation that clinic staff initiate such discussions aims to alleviate reported discomfort and embarrassment (Nixon et al. 2003:266).

While considering embarrassing issues, stress urinary incontinence is very common in female adolescents with CF (Nixon et al. 2002:e22), although under-reported, making it a further topic to be raised by medical staff rather than uneasy young women (Cornacchia et al. 2001:47). To what other issues have they not given voice?

### **Coming of age**

CF is no longer a childhood disease, but has come of age, placing it in the domain of adult medicine, with associated issues of transition, wherein young people with CF leave the safety of known people and facilities in a quasi 'right of passage'. Now that the paediatric setting is no longer appropriate (Madge & Bryon 2002:283), they are entering a new scene that represents not only a wrenching away from things known (Minicozzi 2000:411), but also the converse declaration of having made it thus far. The question arises, how might this progression be for them?

Dubbed a 'process, not an event' (Lewis-Gary 2001:524), the literature highlights a variety of obstacles to a smooth execution of this transition. Some cite a lack of local facilities for adults with CF, despite children being well catered for. Lack can also relate to the amount of interest adult physicians may display (Fox 2002:3); or confidence that non-paediatric nurses convey (Crosier & Wise 2001:30). It may also be the quantity of integrated planning, a factor moderated by family, politics, or paediatricians doubting the abilities of their colleagues in parallel adult services (Fox 2002:3). Sometimes it is simply a lack of funding (Scal et al. 1999:264).

And what of the progression for the young person with CF? Various strategies are detailed in the literature, with a range of documented outcomes (Lewis-Gary 2001:524). Viner (2000:343) recommends a definite plan devised by medical carers,

even when paediatric and adult services coexist, geographical closeness not necessarily ensuring an effective professional relationship. A study report from Cape Town in South Africa expresses concerns and the need for an assessment of patient and parent perceptions regarding transition (Westwood et al. 1999:445).

### **Adults only**

The final size of the adult CF population is a matter of conjecture, there being no reliable mortality rates for those aged over thirty (Dodge et al. 1997:496). It has been estimated that 'a majority of the CF population will be adults by the year 2010 (Kleinhenz & Stanley 2000:71).

And what of adults in the literature? Where are they? Lowton and Gabe (2003) sought some out for a sociological study in southeast England. Analysis and coding using the ATLAS-ti software programme resulted in a portrayal of these people as sometimes feeling a fraud because they have outlived their predicted survival age, and having reached adulthood with what is still considered by sections of the public as a 'child-killing disease'.

Lowton and Gabe (2003) document that little has been written about the experience of adults with CF, despite this representing a 'rich area for inquiry'. Likewise, as new treatments are devised and prognosis changes, existing older studies are becoming inapplicable (Pfeffer et al. 2003:68).

Those diagnosed when an adult, estimated at 9.9% of new diagnoses, (Widerman 2002:45) will have that news conveyed by an adult physician, for whom such divulging is not as commonplace as for a paediatrician. In an interchange with the latter, diagnosis is relayed to a third party - the parents. It is not a rare case, and is readily supported with age appropriate information. Adult respondents in several studies report not seeing themselves in available literature, and a desire to be treated as an adult individual (Walters 2002; Widerman 2003), prompting a call for further research into their unique plight (Widerman 2003:104).

## **Parents' perspective**

Improved survival of children with CF means that families have to adjust and cope with the demands of living with CF for longer (Foster et al. 2001:349). How are they faring?

A core of the literature considers the parents of the CF child, particularly the mother (Carew 2001; Foster et al. 1997). Parents may have negotiated the unenviable dilemma and trauma of possible genetic counselling and antenatal screening, definitive diagnosis representing only the beginning of their experience. How are they portrayed in the literature, and how overt is their contribution to the current body of knowledge?

Parents tend to appear at diagnosis, as people in a state of shock and grief, devoid of knowledge of CF, and seeking accurate, appropriate information (Moore 1988:10). Mothers, especially, are reported as feeling overwhelmed, stunned, with a pervading sense of deep sadness, anguish and bewilderment at diagnosis. Often, the seriousness of diagnosis is gleaned from the faces of attending staff colluding in a perceived 'conspiracy of silence' (p.11). Once again, there exists a comprehensive array of literature around chronic illness, with that specially geared to CF appearing in a minority, with parent's experience often being extracted by an assortment of tools and evidence-based methods. While such endeavours may present a quantifiable foundation on which to construct care, there exists the need for complimentary experiential studies that render understanding that is first hand rather than supposed.

Researchers at the University of Queensland investigating mealtime behaviour also encompassed issues beyond the table (Sanders et al. 1997). Their results include data such as mothers and fathers of children with CF reporting lower parenting self-efficacy than controls. Fathers in this study express lower marital satisfaction.

Consideration of role strain in 33 American couples caring for a child with CF revealed tension in role conflict, childcare tasks and the exchange of affection, but no reliable differences in marital strain in comparison with controls (Quittner et al. 1998). Further papers, however, document maternal depression, paternal withdrawal, and a divorce rate in parents with a child with CF which is double that of both the



general population and of other chronic disorders (Carew 2001:24). Consensus would appear to be elusive on all counts.

### **Stressing the obvious**

A common stressor for these people is the arduous day-to-day treatment, such as medications, physiotherapy (Melnik et al. 2001:548), labelled by one commentator as 'the chronic burden of care' (Ievers & Drotar 1996:49). One American centre's response to this has been the Cystic Fibrosis Family Education Program (Bartholomew et al. 2000), developed from a needs assessment of patients and families, from which performance objectives were derived and validated in a two-stage process.

Simultaneously, several British studies were investigating families living and coping with CF. Coyne's 1997 paper synthesises literature current at that time, highlighting a perceived lack of support for families of chronically ill children, which she attributes in part to a general lack of knowledge among health professionals (p.122). The work examines how families adapt to the illness, its stated goal being to provide indicators for nursing practice and thereby enhancing care and support. Her suggestion that successful management of the illness is the result of 'the family's ability to accommodate the complex treatment into a schedule which permits family activities to continue as before' begs the question: 'is it ever the same?' It is in her conclusion that: 'each family is unique and each family interprets and responds to illness in its own way' (p.129) that I see where my research project can sit.

In anticipation that mothers of CF children would experience higher levels of stress and consequently poorer well being than the normal population, Foster et al. (1997) used questionnaires aimed at evaluating these issues. Contrary to expectations, the study concludes that the fifty mothers in this sample did not differ significantly from normative scores for the United Kingdom population.

Two of these authors subsequently executed a project of a contrasting kind - a qualitative, cross-sectional study, in which in-depth interviews informed a family systems perspective of therapy demands and differential treatment of patients and their families (Foster et al. 2001). They surmise that the impact of chronic illness is

not static, but rather a dynamic occurring in the context of ongoing developmental processes - both of the family as a system and its individual members. To CF itself they attribute a notion of development, having its own progressive course (Foster et al. 2001:362).

A study (Hodgkinson & Lester 2002) in Birmingham utilised semi-structured interviews analysed with the Framework method of analysis to consider the stress and coping strategies that mothers employ, and how nurses might proffer them support. Dubbing nurses 'holders of hope' and 'bridge builders', it suggests that nurses need to look not only at the care of the child with CF, but also to the needs of the mother.

Bluebond-Langer (1996:135) writes of CF as making a significant intrusion on family life, a phenomenon that family members try to contain as they preserve what they can of their normal way of life. This is attempted by making treatment a routine and by the compartmentalisation of information about CF and their child's condition, while avoiding reminders of CF and its consequences. By the redefinition of normal, reassessment of priorities, and reconceptualizing of the future, these families valiantly attempt to live and cope with CF. And I want to ask them: "Tell me how you are going?"

### **A quantified life**

Because of its 'most common' status amongst hereditary diseases, CF is well calculated in all areas of its manifestation. But how is it for those incumbents who are 'surviving against the odds' (Eiser 2003), and 'living on a continuum' (Kerr 2000), the end point of which is clearly and clinically notated in the literature?

Those decreeing a 70% mortality rate in the first year of life for babies born with CF in the 1930's (Andersen 1938) would no doubt be astounded at the contemporary prognosis. For children with CF born in the 1990's, the median survival age is predicted to be 40 years (Elborn 1991:881).

Those with CF, their families and carers, and carriers of the disease 'have an interest in' knowing the current lifespan of the disease, writes Lewis (1998:297), adding somewhat understatedly that so, too, do insurers and healthcare planners. He suggests

that lifespan projections from analysis based on questionable assumptions will be errant. Citing a comparative study between Victoria, England and Wales, Lewis proposes that an 18% better survival rate in the first may not be the result of specialist care but a noted bias in early data from Victoria. That the survival curve in Danish data estimates no deaths for people with CF aged between 35 and 50 renders that data 'just not plausible'. Regarding lifespan, the author concludes it better to acknowledge this to be unknown and to plan with that uncertainty, rather than making decisions on incorrect data (Lewis 1998:299).

The premise that specialist CF care centres deliver better outcomes is debated in the literature. Mahadeva et al. (1998:1771), for example, considered two adult CF centres in the United Kingdom. These investigators divided patients in three categories - those who had always received specialist care, those who had done so only in adulthood, and adults who had received neither paediatric nor adult centre care. Results displayed that: 'we have shown a clear advantage in clinical outcome in patients who received treatment in CF centres', the maximum benefit of large, dedicated units being apparent in nutrition and pulmonary disease severity (p.1774). The British Medical Journal follows this report with an immediate rebuttal, in which Dodge (1998a:1775) critiques the methodology and inherent selection bias, cautioning against generalising from these data. Concluding that CF centres vary in leadership, resources and outcomes, Dodge indicates the need for better insight into the components of specialist care, rather than defining centres in terms of clinic size.

In Australia, the John Hunter Hospital is the setting of a study (Collins et al. 1999) seeking to assess the impact of lifetime continuous care at a specialised CF centre on growth and lung function. It would purport an association between such consistent care and improved growth, but no improvement in lung function.

Blest's (2000) analysis of Australian survival data in state-based 10 year cohorts between 1968 and 1977 rates Tasmania poorly in comparison with the others. Surprisingly, however, Tasmanian survival dramatically improved between 1978 and 1998, being 'indeed the best in the country'. The rationale for this profound development is not clear. It is a difficult trend to explain, considering the consistent intent of international studies to highlight dedicated tertiary centres as the ideal for

achieving maximum CF survival rates, such centralised care never having existed in Tasmania (Blest 2000:51). Thus the 'big is better' notion is tempered by the fact that such centres facilitate the liberal spreading of *Pseudomonas aeruginosa*, an acknowledged predictor of mortality in those with CF (Rosenfeld et al. 1997:794).

A comparison of CF incidence between that of Tasmania and South Australia invests the former with a rate 2.5 times higher than the latter and one of the highest rates in the world (Blest 2000:42). Evidence suggests that the occurrence of CF is higher in Celtic regions, such as the republic of Ireland, Scotland and Brittany (Brock et al. 1998). Likewise has been demonstrated a higher incidence in children of Australian parents (90% of whom are British decedents), compared with those of Italian or Greek-born parentage (Allan & Phelan 1985). By synthesising these data with those displaying Tasmania's predominantly Caucasian origins, Blest (2000:51) postulates that the high incidence of CF in the state may be attributed to Anglo-Celtic roots.

### **A world view**

What becomes apparent from a reading of the literature on CF from various regions of the world is not only a diversity of occurrence, but also of knowledge, treatment availability and survival. Thus centres such as the United Arab Emirates are depicted deciphering their genetic incidence (Frossard et al. 1999:496), Croatia decoding its karyotypes (Tanackovic et al. 2000:333), while Japan reporting 130 cases of CF during the last five decades (Yoshimura et al. 1999:173) confirms its infrequent incidence - 1 in 350 000 compared to 1 in 3500 in the USA (Iwasa et al. 2001:467). This correlates with the conjecture that CF is rare in Asiatic populations (Yamashiro et al. 1997:544).

Since the identification of the CF gene in 1989, more than 650 mutations have been detected (Raskin et al. 1997:499). Greek scientists have identified 48 mutations, which include 8 novel ones, in their population (Tzetis et al. 1997:121). Brazil reports variations between its states, reflecting its colonisation by Portugal in the sixteenth century, and migration from Italy, Spain and Portugal in the nineteenth (Raskin et al. 1997:500).

A World Health Organization memorandum (1997) alerts the researcher to a differing tale in some countries. Some nations are debating the efficacy of various treatments and the location of the centre from which they are administered. There are, however, developing countries where CF services are embryonic or non-existent, in a milieu of under-diagnosis, reduced life expectancy compared to developed countries, and meagre availability of vital medication.

Such a picture is painted in the Former Soviet Union, where those with CF expect no more than sixteen years of life (Chambers 2002), and one doctor reportedly gave up treating CF children because he could not obtain the necessary medication. Even then his patients would seem to be a step ahead of many there who remain undiagnosed because the condition is not widely known in primary medical centres.

Discrepancy is not restricted to national borders. A study of incidence and severity of CF in black Americans reports that they have a low incidence of 1 in 15 000 compared to 1 in 3 200 in their white counterparts. They are, however, currently younger and have poorer nutritional status and pulmonary function (Hamosh et al. 1998:255).

Writing in the New York Times, Wade (1997:5) reports that, along with a dozen other genetic diseases, CF is more common among Ashkenazi Jews - those of European descent who account for the majority of American Jews - than other population groups.

From the current literature, it is evident that a lower income (O'Connor et al. 2003:333), uninsured female with CF (Curtis et al. 1997:1921), unable to access a tertiary medical centre, will have a reduced lifespan (Mahadeva et al. 1998:1771). Likewise I could quote the definitive dossier on CF - incidence, survival and mortality. I could reduce these to Australia, to Tasmania (Blest 2000), but I would be acquainted but unaware, well informed but uninitiated; able to relay statistics - even analyse those figures and bind them with assumptions and conjecture to build care strategies upon them - yet fail to glimpse the person behind each one of those statistical units.

## **QOL's**

The attempt to quantify these peoples' experience is documented in the literature as Quality of Life (QOL) studies. Definitions of quality of life differ from 'the sum of physical and psychosocial functioning from the patient's point of view' (de Jong 1997:95), to a more sociological notion of fulfilment of the individual's expectations in life (Anderson & Burckhardt 1999:299). Discussion centres on the efficacy of the instruments utilised in its assessment. Staab et al. (1998:728) surmise that there is no consensus on whether to use those that are generic, or alternately disease specific, to assess health related quality of life; the former focusing on disease specific states, the latter permitting a broad comparison. While the majority of CF patients in their German study displayed an apparently realistic perception of their health in comparison to their physical predictors, others with supposedly little impairment considered their health to be bad, thus highlighting the importance of forming a complete picture by the inclusion of subjective cognitive factors.

Children are often considered unreliable respondents, and thus their quality of life has tended to be rated by others (Eiser & Morse 2001:207). Both generic and disease-specific paediatric measures are, in some cases, a downscaled adult version, and thus not entirely appropriate (Eiser et al. 2000:403). Those few instruments suitable for children tend to draw on the opinion of a parent or carer. That little concordance is found between child and proxy estimation demonstrates the need for child self-assessment (Gerharz et al. 2003:150). One such tool is the PedsQl (Varni et al. 1999:126), which draws upon both child and parent perceptions, although its inception from work with children with cancer is revealed in the issues with which it deals. While acknowledging the value of such tools in the evaluation of changes in the quality of life in children as the result of interventions, Eiser et al. (2000:411) suggest that a more creative approach to eliciting information from young children is likely to be useful.

An Australian study (Meuleners et al. 2002) of chronically ill adolescents' quality of life sought the perception of parents, teachers and health professionals regarding sixteen items they rated as important. The Delphi methodology was 'a useful technique to determine consensus amongst the study participants', the authors

concluding that perhaps further investigation should seek the views of the adolescents themselves (Meuleners et al. 2002:47).

While some studies demonstrate a strong correlation between disease severity, treatment and quality of life (Anderson & Burckhardt 1999; Meuleners et al. 2002; Staab et al.1998), others would say that no such relationship exists (de Jong et al. 1997:98). In response to their observation that health related quality of life in adults with CF has been measured either using generic scales or respiratory measurements, Gee et al. (2000:946) deduce that such calculations do not reflect areas of concern that are specific to an adult with CF. After consulting adults as well as adolescents with CF, they have devised a fifty-two item dossier, across nine domains, covering physical and social functioning, plus CF-specific issues - symptoms, treatment and body image.

Anderson and Burckhardt (1999:298) call for a valid conception of just what is quality of life, before measurement can be considered. They declare there to be no consensus in the health care disciplines, but rather confusion and controversy, and an assortment of instruments that do not measure a single phenomenon (p.299).

### **Transplant: One lung or two?**

There comes a point in the course of CF when no matter what means is used to measure quality of life, it has obviously dissipated, and the option of lung transplant may be offered.

Transplant has certainly come a long way since the first in 1963, the initial paediatric one being attempted in 1987 on a 16-year-old (Mendeloff 2002:277). Lack of donor organs, however, continues to be a hindrance to most heart-lung transplant programmes (Balfour-Lynn et al.1997:40).

Since the mid 1980's, nearly 400 CF patients in the United States have undergone lung transplantation (Yankasakas et al. 1998:217). As the utilisation of this procedure grows, so too does the disparity between organs required and organs supplied, with CF patients having noted disadvantages in the allocation process. The suppurative nature of their lung condition requires double lung transplantation, a procedure that

not all American centres offer because of the increased complexity of managing CF patients compared to others (Yankasakas et al. 1998:219).

As one reads on, however, tempering words become evident. Firstly, lung transplant is neither cure nor panacea (Kurland & Orenstein 2001:1419). In the case of CF, it has been described as the trading of part of one disease for an entire second disease state including diabetes mellitus, drug induced toxicity and renal damage, infection of the new lungs by naive bronchi, and the ultimate rejection by the new host of the perceived invading organs. Any mild increase in cough or fall in pulmonary function which before transplant may have been inconvenient, now require constant vigilance and amplified concern as they portend rejection or infection of the new organs (p.1420).

An Australian retrospective analysis of the first one hundred CF patients receiving cadaveric lungs at St. Vincent's Hospital shows that candidates waited an average of 244 days for surgery. Post transplant survival rates at 1 and 7 years were 92% and 56% respectively (Morton et al. 2003:119). A Western Australian study reviews adults with CF who need to relocate to an eastern state transplant centre. It concludes there is an increased burden for those people, 11.5% of whom died while awaiting surgery (Morey et al. 2003:121).

In the United States, allocation of donor organs is unaffected by disease severity, being instead according to time on the waiting list. Those with CF are at a distinct disadvantage, potentially being overtaken by an emphysema patient who has not endured a lifetime of disease and anticipation of a transplant procedure, nor for whom is waiting list mortality as high (Stewart & Patterson 2001).

The British system sees the allocation of organs being made by a senior member of the transplant team, with priority given to patients with the worst clinical status. A study (Serrano-Ikkos & Lask 2003) in that country deduced that there was no correlation between pre-existing adverse psychosocial factors and transplant survival, an important issue considering that clinicians responsible for appropriate allocation of scarce organs will use these as contraindications, considering the increased stress of



transplant to compromise survival. Such a conclusion, however, does not acknowledge the unique and varied individual response to difficult circumstances.

An ethnographic study (Durst et al. 2001) of adolescent responses to lung transplant concludes that as time passes, the recipient begins to realise that the transplant is not some 'magical cure' once hoped for, but actually initiates other chronic conditions. How do they deal with such a realisation?

A procedure imbued with both high costs and high risks, lung transplant improves survival for a minority of CF patients for whom it renders a 5 year predicted survival rate of fifty percent (Dickinson-Herbst 2001:88). Vittone (2001:92) asks whether success is measured as quantity or quality of time post transplant. 'Is success "life prolonging only?"' - a question that begs asking of those most intimately acquainted with it.

A study (Serrano-Ikkos et al.1999) at Great Ormond Street Hospital for Children in London examines the fact that because transplantation is not curative, it presents such children and their families with innumerable physical and psychological stresses post-transplant. Despite their discovering a 'new way of life' and participation in a full range of new activities, sizeable numbers of such children are considered to be at risk of psychosocial impairment.

### **Cast in a new role**

Post transplant, change also comes in the transition of a chronically ill CF patient to a robust individual. Yankaskas et al. (1998:225) suggest further research into what enhances or undermines this process wherein some patients find it difficult to relinquish their 'symbols of illness' (Kurland & Orenstein 2001:1420). Likewise some family members struggle with functional identity as the person around whom care - and often family dynamics - has been attuned has now been cast in a new role, and other members are forced to reassess their own positions.

Consideration of the personal experience of the transplant process tends to be represented in the literature in third person case study format (Baily 1998; Ferrin et al. 2001; Stanghelle et al. 2000) wherein an exemplary story is used to consider a

common issue. By example, the delivery of palliative care while awaiting new lungs is discussed by a nurse coordinator in light of a thirty-two year-old man for whom she has cared (Ferrin et al. 2001). The process of double transplant is personified in fifteen year-old 'Jessica' (Baily 1998), and transplant success is celebrated in the Danish report of a young man whose new lungs transformed a 'chronically ill CF patient into a robust marathon runner' (Stanghelle et al. 2000).

### **Refusal may offend**

The notion of refusing lung transplant has not featured on research agendas, and may represent a severe blow to both a family and a medical team who have been committed to the prevention of deterioration and prolongation of the life of the person with CF (Gotz, I. 2003). Such a resolve may have been precipitated by the death of a fellow patient, or simply weariness with suffering. It is also a decision that needs to be considered reversible. A change of mind in regard to undergoing a lung transplant may be in response to negative factors, such as rapid deterioration and the realisation that they do not want to die; or those of a positive, hope-engendering kind, like falling in love or finding an exciting new job.

Because of the shortage of available lungs and the exacerbation of disease, half of those with CF will die while taking their place in the transplant queue (Serrano-Ikkos & Lask 2003:49). There exists the double bind that patients need to be in their last two years of life - sick enough for transplant yet able to cope with the trauma of surgery. Likewise they can be subjected to the dichotomous predicament of waiting for lungs and being denied palliative care and preparation for death.

### **Coming to an end**

While all humans realise their mortality, for most it is not a matter of quantification, conjecture and hope as it would seem to be for the person with CF, whose lifelong attempt at surviving 'against the odds' (Johannesson & Lask 2003) will end in defeat. It is estimated that in the United Kingdom, three young people die from CF each week (Elborn et al. 1991:881). In other life limiting conditions, such as carcinoma, the cessation of rigorous treatment in favour of those affording comfort is an inevitable step. In contrast, a study at Boston Hospital (Robinson et al. 1997:205) found no such clear transition of care for those with CF. Rather, it deduced that a combination of

preventative, therapeutic and palliative care is applicable. The 'waxing and waning nature' of end stage CF renders it an indeterminate state, in which the continuation of the familiar lifelong regime of medications not only delivers relief of a physical kind, but also that of psychological familiarity. Having probably been closely associated with the death of friends, those with CF will often have both specific requests and fears regarding their own demise (Jefferson & Davies 1998:110).

The notion of concurrent preventative, active and palliative care is examined by Lowton (2002), who critiques the false dichotomy wherein a patient is considered to be either a candidate for transplant or dying, such a delineation sometimes being fostered through conflict between transplant and palliative care medical teams. She recommends the identification of the needs of adults with advanced CF and their families, such research suggesting how these could be met.

### **Popular press**

Those who have cared for someone with CF will consider themselves acquainted with this disease. What might be the understanding of those who are not? The media is identified as an important source of information on health (Petersen 1991:135), and CF would seem to have all the makings of good copy. Not only is its causation of interest in the current climate of genes and inherited risks, but it lends itself equally to so called 'hard' news, wherein serious, fact-based coverage of disease privileges high status official sources; and 'soft' news, dubbed the human interest story, in which real people display its outcome (Henderson & Kitzinger 1999:568).

The manifestation of CF as personal experience is documented in explorations in the form of video, magazine biographical accounts and photographic portrayal. A young Melbourne woman's plight of awaiting a donor of heart, lungs and liver, as aired on *A Current Affair* (April 2, 2003), is couched in formulaic emotive music and wedding photo backdrop. Jody and Anthony are teenage sweethearts whose daily routine of physiotherapy and copious medications are keeping her CF in check and her alive in anticipation of this 'never been done before' surgery. In closing this poignant depiction cum subtle plea for organ donation, compere Ray Martin promises to keep the viewers up to date with Jody's progress.

Conjecture hangs over her outcome, however, because when the news of Australia's first triple transplant surgery was announced, it was a young man who was emblazoned on the cover of Brisbane's *Courier Mail* (August 5, 2003). CF provided abundant material for journalists seeking either the hard scientific details - 'Transplant a Success' (Fraser 2003:4) - or human interest accounts - 'Triple transplant first gives hope to dying man' (Edmiston 2003:1).

Following a similar format as *A Current Affair*, but in hard copy, *The Australian Women's Weekly* (Chisholm 2000:76) presents a double scoop entitled 'Fight of a lifetime'. After taking the eye through a wedding portrait and a 'happy now' snap embedded behind the tube-infested hospital shot, the story unfolds of another young woman with CF whose success tale of lung transplant and marriage was not the end, as a subsequent car accident potentiated rejection of her new organs. The reader is certainly acquainted with the recent sensational aspects of her journey, but is not privy to the years of daily experience with CF, it being encapsulated in one neat metaphor - 'everyday was just another mountain I had to climb' - not the material that popular magazines see as compelling journalism.

*Still Breathing* is the provocative title given to a documentary screened on SBS (August 25, 2003). Having all the makings of not only inside hospital drama but also romance - he marries his nurse - Rob's personal account of living and dying with CF is a 'real TV' snapshot. He equates his projected short life with dog years, deducing that at thirty he is really ninety in canine years. Unlike other media presentations, doctors are not heroes in this piece, but rather those who: 'see death as some looming giant ready to pounce as soon as they do something wrong ... kinda striving for immortality in their patients.' Rob, however, would say that it is a matter of your time being up, dying young at least ensuring that 'you are quite good looking in the coffin'.

David and Paul Bissell, twenty-seven-year-old identical twins with CF, have featured several times on television programmes. *Australian Story* (July 7, 2001) presented a candid interview with them and with their wives, who, in a sense, live vicariously with CF, and have considered such issues as not having children and not 'growing old with the one you love'. The following year the twins reappear in the media, this time in their professional role as clowns, presenting the human interest story for an episode

of *Dimensions* (October 31, 2002), in which George Negus describes these ‘incurably brave, incurably funny’ young men as being on ‘borrowed time’.

Such media representation is certainly a contrast with articles such as ‘Designer Babies’, in which it is declared that ‘The time has come for parents-to-be to create a baby free of defects’, this local newspaper proffering genetic testing as a way to ‘eliminate ... lethal diseases such as cystic fibrosis’ (Krieger 2002:33). While reporters bring their interpretation of CF to public light, how do readers and viewers perceive not only this disease, but more importantly, the life experience of those for whom it is not a tabloid titbit, but a daily reality? What might be their side of the story?

### **And so?**

Having scanned the current literature on CF, one can but imagine what that of the future will report. Whose will be the dominant voices? While those controlling care and administering investigative tools do so in the interest of those affected by CF - children and families - my literary investigation has left me still asking: “What is their experience of living with CF?”

Confirmation of this query from not only practice colleagues, but also from my reading of the literature, led to my reflection upon an appropriate methodology through which to pose it. Discussion of my deliberation is presented in the next chapter.

## **A phenomenological perspective: passé or prophetic?**

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The Road goes ever on and on  
Down from the door where it began.  
Now far ahead the road has gone,  
And I must follow, if I can,  
Pursuing it with eager feet,  
Until it joins some larger way.

- J.J.R.Tolkien

So how was I to deliver the insight that nursing colleagues sought? What methodology would bring to light the stories I had a sense needed telling - the experiences of the children with CF and their families? I needed a way to slip inside their context and capture those unreflected-upon experiences that they may never have previously considered.

### **Matters methodological**

Concurring with van Manen's (1990:2) exhortation to select a research methodology which maintains a certain harmony with the deep interest that makes one a researcher in the first place, I have utilised phenomenology, which aims at gaining a deeper understanding of the nature or meaning of everyday experience, and echoes my question 'What is this experience like?' (p.9).

What is this phenomenology? A closer encounter reveals that it leaves behind the bounds of method, and is, rather, a philosophical attitude - a way of relating to and dealing with, the lives of those who come within the field of its gaze. A physical scientist might place a notated specimen under a high-powered lens and submit cold, hard data to a system of analysis. The person phenomenologically attuned will go from their world into that of the other and seek to capture their pre-reflective thoughts, submitting these to scrutiny before they have been subjected to personal analysis or rationalisation on the part of the raconteur.

Phenomenology is a research approach - the study of lived experience - a process driven by philosophical assumptions on the part of the researcher rather than by prescribed method (Munhall 1994:34). Not solely a writing activity, the lens of inquiry can be widened by drawing upon human experience as depicted in art, film, photography, literature and poetry (p.38). As I delved into it further, I realised the potential and scope that phenomenology affords a researcher. This set a seal on the efficacy of my approaching those living with CF in this nuance.

While the human science researcher needs to understand something of philosophical tradition, this does not imply that they must become a professional philosopher. Rather they should be sufficiently *au fait* with their nominated sphere in order to articulate the implications of a phenomenological research endeavour (van Manen 1990:7). In so doing, I found that phenomenology is by no means a neat 'homogenous entity' (Darbyshire 1992:39), but rather reflects a diversity of thought that defies a single definition (Misiak & Sexton 1973:3). Those seeking an in-depth philosophical exposé would be better served by consulting texts so dedicated. This chapter conveys the philosophical focus that underpins the study and guides its execution, and whilst not being method *per se*, is somewhat of a *modus operandi* for firstly approaching participants, and then for synthesising the experience conveyed to me. You, the reader, will then engage with my writing, and the process continues as I aim to elicit an acquiescent response from you - the 'phenomenological nod' (van Manen 1990:27).

### **Philosophical conception: an historical account**

Leaving the safety of structure and prescriptive steps well behind, I began my investigation of philosophical tenets in order to decipher not only what they might be, but where I would situate myself within them. Thus I found myself plunged into Germany of the early 1900's and days of hallowed halls filled with philosophers musing on life, on experience, on object and subject. Picture the debate as these philosophers reacted to the legacy bequeathed them by the so-called Age of Enlightenment of the eighteenth century (Grossman 1984:69) whose thinkers, influenced by the rapid progress in science, developed boundless faith in the power of reason.

It was in reaction to such notions that Edmund Husserl (1859 - 1938) perceived the world to be in intellectual and scientific crisis (Carr 1974:45). As a result, he sought to free his thought and philosophy from the Enlightenment movement which considered:

Ideas in no way allow us to know beings as they actually are; they merely depict them in terms of their relationship with us, and this alone is enough to prove the vanity of the efforts of those philosophers who pretend to penetrate into the nature of things.

(Condillac, 1754, *Traité des Sensations*, cited in Hampson 1968:75)

Husserl's influence not only impacted the thought of his contemporaries, but continues to be acknowledged through subsequent eras, being foundational to current phenomenology, and, by implication, to this study.

**'Ladies and gentlemen, honoured colleagues, dear comrades!'**

Thus began the young Husserl's inaugural address as rector of the University of Freiburg im Breisgau in 1917. He went on to declare:

A new fundamental science, pure phenomenology, has been developed within philosophy. This is a science of a thoroughly new type and endless scope. It is inferior in methodological rigor to none of the modern sciences. All philosophical disciplines are rooted in pure phenomenology, through whose development, and through it alone, they obtain their proper force. Philosophy is possible as a rigorous science at all only through pure phenomenology.

(Husserl 1917:10)

Dubbed the founding father of phenomenology (Macann 1993:59) and a philosophical mentor to subsequent philosophers (Stewart & Mickunas 1974: 15), Husserl first outlined phenomenology in his *Logical Investigations* in 1900. He was conferred a doctorate in mathematics from the University of Vienna at the age of twenty-four. It was here that the noted philosopher, Brentano, turned the novice Husserl's attention to studies of a philosophical nature. There followed the publication of his *Philosophie der Arithmetik* in 1891, which Husserl later professed to being a complete failure - or was it? For it was this inquiry into the origins of numerical concepts that caused him to consider the nature of the numbers themselves - as timeless, non-spatial entities (Grossman 1984:91). Properties of numbers led to his considering further aspects of being - a realm of existence and relationship. How could such a sphere be known?



## **Cartesian carvings**

Phenomenology is what it is because it neither seeks nor accepts evidence other than that offered by consciousness itself. Husserl (1965:68)

René Descartes, an intellectual revolutionary of the seventeenth century (Hampson 1968:18), is charged with neatly slicing reality into two easy chunks - mind and body. With a resultant shift away from conscious experience to objective reality, consciousness could be investigated by the methods of observation of the natural sciences. Descartes and Husserl were both mathematicians who were unwilling to accept the status quo of the philosophy of their time. Husserl, however, proffered critique of Descartes' stance, formalising this in his *Cartesian Meditations*, originally penned in 1929 but first published in 1950 (1999). In this work, Husserl writes that the separation of thinking substance (*res cogitans*) and extended substance (*res extensa*) - mind and nature - leads naturally to the challenge: what is the relationship between the two (Stewart & Mickunas 1974:20)?

## ***Zu den Sachen selbst ... Back to the things themselves***

'The impulse to research must proceed not from philosophies but from things and from the problems connected with them,' declared Husserl (1965:146). For him, phenomenology was 'above all a method and an attitude of mind' (Carr 1974:39), a fresh look at the reality he wanted to understand and explain (Crotty 1996:30). In order to delineate the perspective needed for phenomenological inquiry, Husserl employed three metaphors - phenomenological reduction, bracketing and *epoché*, an understanding of which will clarify what 'going back to the things themselves' might entail.

## **Phenomenological reduction**

Phenomenological reduction, described by some as idealistic, is the narrowing of attention to what are the essential components of experience. Such a reflection requires what Husserl dubbed 'eidetic' - from the Greek *eidos* meaning an idea or form - a laying aside of the particulars in order that the universal essence might be revealed (Crotty 1996:61). By way of illustration, Crotty effectively utilises the analogy of the reduction of metal by the separation from it of all non-metallic

substances, by the process of purification. He likens that to the idea Husserl held for the purification of one's consciousness from the so-called 'dross' of the natural attitude. How is this to be achieved? - by the suspension of belief in the actual existence of the objects of experience (Crotty 1996:59). Husserl labelled this process 'bracketing' - a term that flowed neatly across from mathematics, wherein a part of an equation is placed in parentheses to be held in exclusion of the current calculation under consideration (Stewart & Mickunas 1974:91). The intention of this bracketing is not to limit experience to those things that are indubitable, but rather to render access to experience by holding in abeyance those suppositions that can limit it (p.48).

Bracketing or suspension of the natural attitude Husserl also dubbed the *epoché*, from the Greek word utilised in Stoic philosophy to refer to the abstention of belief (Stewart & Mickunas 1974:7). 'I must lose the world by *epoché*, in order to regain it by a universal self-examination', he wrote (Husserl 1999:157). Despite these idealistic notions of separating out the object under investigation, Husserl realised that not everything can be bracketed, because it is a process undertaken by a self which can never be bracketed, leaving a phenomenological 'residue' - the 'transcendental ego' (Stewart & Mickunas 1974:92). The natural attitude, as described by Husserl, postulates the independent existence of the object under attention.

### **Intentionality**

It was from his association with Brentano that Husserl drew the concept that consciousness is, by its very nature, a consciousness *of*, that is, intentional (Macann 1993:3). A concept grasped only by divesting it of colloquial meaning of forward planning (Crotty 1996:38), intentionality is the notion that all acts of consciousness are related to, or point to, something. Love, for example, requires someone or something to be loved. Likewise, perception does not exist without something to be perceived (Misiak and Sexton 1973:9). A thought is a thought *of* something, as the human mind reaches out, into the objects of which it is conscious (Crotty 1996:38).

### **Language**

At this point a consideration of language is appropriate, as it has been a barrier to understanding Husserl's work. The introduction to a work of Husserl's (1965:7),

translated in the 1960's, is prefaced by the translator decrying the lack of availability of the philosopher's writings in English. It would seem that this did not signal a disinterest in his work, but rather resulted from the difficulty of translating texts. Describing Husserl's style as 'extremely involuted and, therefore, forbidding', his translator concluded that even German readers acknowledged his style to be difficult, 'quite un-German' in fact, with that particular translator nominating accuracy over eloquence when translating from a language in which many unique words have no identical English equivalent. From its onset, it would seem that phenomenology has been filtered, interpreted and moderated by successive translators, with the potential for discrepancy and controversy being inherent in its roots.

While Husserl's concepts - when understood - would seem to have received a positive response, his being Jewish in pre-war Nazi Germany evoked a negative one (Stewart & Mickunas 1974:11). He was replaced in his university position by one of his former pupils (Steiner 1978:151), and thus the propagation of phenomenology was facilitated by causes political, perhaps more so than philosophical.

### **What is is**

Husserl's student, the young Martin Heidegger, discerned another facet of humanness - one which for him held greater validity than that espoused by his teacher/mentor. He has been dubbed the most original and influential twentieth century philosopher by several commentators (Dreyfus 2002:1, Sluga 1995:239).

Heidegger encountered the work of Brentano as an eighteen-year-old pursuing studies at a Jesuit secondary school. This precipitated his quest to grasp the meaning of being (Crotty 1996:65).

### **To be or not to be: that is the question.**

Do we in our time have an answer to the question of what we really mean by the word 'being?' ... we must reawaken an understanding for the meaning of this question. (Heidegger 1962:1)

So begins Heidegger's *Meisterwerk, Being and Time*. Intended to be the precursor of a more extensive programme, it caused much discussion upon its release - particularly

for a first work (Macann 1993:57). Utilising the two crucial vantage points of metaphysics after Plato, and of science and technology after Aristotle and Descartes, Heidegger deduced that the history of Western civilisation was actually the story of how being came to be forgotten (Steiner 1978: 42). 'We ... who used to think we understood it, have now become perplexed', he wrote (Heidegger 1962:1). Thus Heidegger took a step back from Husserl's thesis of lived/everyday experience - epistemological inquiry - to the posing of questions no longer experiential. Rather, he pursued ontological inquiries - those concerned with what it means to *be* (van Manen 1990:183). Heidegger (1962:62) acknowledged that such an investigation would not be possible without the groundwork done by Husserl, although he relegated that work to the status of a preliminary conception of phenomenology. For Heidegger, standing higher than actuality was possibility, and only by seizing upon *it* could phenomenology be understood.

Over time, his use of the word 'phenomenology' gradually ceased (Crotty 1996:65), prompting some commentators to nominate it a phase through which he passed (Spiegelberg 1982:409). That the embracing of this philosophy led to Heidegger's aligning himself with the Nazi Party is an issue highlighted and explored by some commentaries, or blatantly ignored by others. His political engagement has engendered a questioning of connections between it and his philosophical work, with inconclusive results (Sluga 1995:7). His academic career was moderated by his political alignment, which saw him barred from teaching after the end of the Second World War. Such a ban by no means brought a halt to his work, but rather saw it channelled into writing and publishing, affording him not only a broadening profile, but also a changing perspective. It is certainly acknowledged that the Heidegger of latter years had moved from a stance philosophical to one poetical, considered by some to be religious or mystical (p:239). But for now, back to the question of being - the point to which Heidegger sought to return.

### **Being .. Dasein**

Heidegger calls human reality *Dasein*, meaning 'being there', as opposed to *Sein*, which refers to ontological Being (Stewart & Mickunas 1974:69). *Dasein* is itself no fancy term, but rather a German, almost colloquialism, for 'existence', meaning 'being-there'. Heidegger utilises it to indicate human being, not a human subject *per*

se, but as the locus where Being manifests itself (Crotty 1996:102). 'All research', he (Heidegger 1962:41) wrote, 'and not least that which operates within the range of the central question of Being - is an ontical possibility of Dasein. Dasein's Being finds its meaning in temporality'. Later works are more concerned with *Sein* rather than *Dasein*, reflecting the subtle shift in Heidegger's reflections (Stewart & Mickunas 1974:70)

### **Sorge - concept of care**

Whereas Heidegger perceived *Dasein* as the place where Being is revealed, the basic mode of *Dasein* he dubbed *Sorge* - care (Stewart & Mickunas 1974:70), the most fundamental state of one's 'Being-in-the-world' (Zhang 1993:307). This care, as in 'being concerned', refers to the different ways one relates to others and entities in one's world (Crotty 1996:84). Heidegger depicts this lifestyle approach as being either neatly authentic - when people freely chooses their way of being-in-the-world; or, conversely, inauthentic - when people live subject to the opinions and expectations of others. Thus individuals existing authentically are able to avail themselves of free choice, imbued with not only insight into their situation, but also the language with which to frame it. Those living inauthentically, however, are dogged by certain ambiguities, manifested in a lack of understanding as well as an inability to utilise speech as a way of reconciling their predicament (Stewart & Mickunas 1974:70).

### **Time**

The further one delves into it, the clearer becomes the understanding of why a work on the meaning of being is entitled *Being and Time*. Heidegger (1962:38) sees the two as inextricably linked, with the latter as the horizon for all understanding and interpretation of the former; and the sphere in which being is determined temporally (Von Herrmann 1993:120). Heidegger disclaimed any Husserlian influence on his theory of time, despite his having edited his teacher's writings on the phenomenology of internal time consciousness. Both philosophers, however, claim that the structure and analysis of time cannot be disconnected from the self. For Heidegger, time could not be analysed in isolation as he regarded it as integral to existence (Macann 1993:96).

## **A word about language**

The reader is not too far into the book *Being and Time* without confronting Heidegger's original language, to which its translators give acknowledgment in the Preface by way of a preparatory word of warning. They describe his tendency to discard traditional philosophical terminology, utilising instead a vocabulary of his own - one in which he coins new expressions from older roots, and uses adverbs, prepositions and pronouns as nouns. He freely employs the same word to evoke various meanings, with a generous use of what one commentator dubbed 'uncouth chains of hyphenation' (Steiner 1978:15). As with Husserl before him, even speakers of his native tongue have been denied a fluent read, grappling to always apprehend the concepts he sought to convey.

Considering the philosophical significance of translation, Heidegger describes it as a type of interpretation, not merely the objective exchange of one word for another. The dictionary he considers to be subject to a particular stance and interpretation of language, and therefore not a reliable arbiter of definition (Emad 1993:325). It is in his deeper exploration of language that Heidegger seeks, however, to explicate human discourse, nominating language as having its roots in the existential constitution of Dasein's disclosedness - the means by which Being comes to revelation (Heidegger 1962:203). With philosophical imperatives established, how did Heidegger propose their explication?

## **Hermeneutics**

It was Barth's 1918 commentary on The Epistle to the Romans that alerted Heidegger to the efficacy of word-by-word interpretation of text (Steiner 1978:73). As is his wont, Heidegger takes this word and gives it new meaning. Originally referring to 'interpretation', and being a systemic approach to the interpretation of oral and written texts, Heidegger proposes that everyone exists hermeneutically, in a process of finding significance and meaning in the world (Crotty 1996:102). Thus he defines a means of access to that existence.

A hermeneutic inquiry is by nature a holistic pursuit because a phenomenon is examined within the context in which it originates. Brackets are abandoned, and one

is invited to 'leap' into the arena of understanding - the so-called hermeneutic circle (Heidegger 1962:363).

### **'Charge of circularity'**

Heidegger (1962:195) stresses the importance of entering this circle in the right way - a sort of invitation to 'come on in'. He cautions, however, that it is not the orbit of any random knowledge, but rather an existential manifestation of the '*fore-structure* of Dasein itself'. He sees within the circle the potential for 'the most primordial kind of knowing', grasped not by 'fancies and popular conceptions', but by interpreting these fore-structures in terms of the things themselves.

In describing the hermeneutic circle, Heidegger was by no means initiating a new concept. It appears in the works of the nineteenth century philosophers Ast, Schleiermacher and later, Dilthey. In a style true to his innovative form, Heidegger harnesses the concept and invests it with a new meaning (Crotty 1996:82).

So how does the novice philosopher recognise this circular dynamic? The hermeneutic circle is a reflection of the relationship between the whole and its parts, and the notion that one of necessity gives meaning to the other. That is, to know an individual part, it needs to be considered within the context of the whole that endows it with characteristics. Likewise, the sum total of the parts complete and give meaning to the whole (Geanellos 1998:159).

An often-used example is of a sentence being in essence the group of its constitutive words, whose meanings are explicated from within that context (Geanellos 1998:159). So as you read this statement, you derive its meaning from those nouns and verbs which make it a sentence, developing your understanding of those parts of speech by their interrelationship within it. On their own, they would afford you little clue as to their interpretation and would be devoid of purpose. For Heidegger (1962:191), interpretation is 'never a presuppositionless apprehending of something presented to us', but is subject to the 'obvious undiscussed assumption' of the interpreter. It is in context of what we already know that we understand. Heidegger describes pre-understanding as a fore-structure, rather than a background, consisting in 'fore-having', a 'fore-sight' and a 'fore-conception.' (Crotty 1996:87).

What had been an epistemological and methodological device had now been processed by Heidegger into a way of describing the ontological nature of understanding (Geanellos 1998:160), which would be harnessed in the work of subsequent phenomenologists. Heidegger garnered from Husserl phenomenological notions and by a process of refining some and refuting others, he precipitated the movement on its developmental trail.

### **New horizons**

While Heidegger was influencing the course of phenomenology, his work was being observed by Hans Georg Gadamer, a student of his in the 1920's. Yet again the phenomenological path wended its way via the relationship of master and apprentice.

Gadamer's major work *Truth and Method* (1975) is rather incongruously so called because it is not a prescriptive recipe for studying human experience. He considers a preoccupation with method incongruous with what he terms the true spirit of human science research (van Manen 1990:3). For Gadamer, as for Heidegger, the possibility of coming into a research situation with neither preconception nor current knowledge and, in fact, deliberately leaving those as it were, at the door - the Husserlian notion of bracketing - he deemed impossible.

'I always feel uncomfortable', reveals Gadamer (1996:139), 'when people expect the philosopher to be presumptuous enough to claim to know what nobody else recognises or understands ... philosophical thinking consists in making what we already know another step conscious', a drawing on what we already think. This he depicts as being deposited in language, waiting to be grasped (p.115).

### **In my view ...**

Heidegger considers that understanding others comes through their language and history. A researcher is not naïve of the world of the participant, but rather brings to the research endeavour pre-understandings that Heidegger deems essential to interpretation (Walsh 1996:234). Building upon this concept, Gadamer (1975:239) extends and formalises Heidegger's proposition by his description of prejudices. He re-examines the notion of a prejudice, calling for the recognition of those he dubs 'legitimate', as he reinvests the term with a positive connotation (Gadamer 1975:246).



It is prejudices that constitute the horizon of the present, delineating current vision, which is in a state of perpetual reformation as prejudices are continually re-tested (Gadamer 1975:273).

Just as in the natural world, the interpretative world is not finite. Upon reaching the visible horizon, the explorer finds it has gradually dissipated, only to be presented with another one to be attained. Horizon, the 'range of vision that includes everything that can be seen from a particular vantage point', is by no means some 'rigid frontier' (Gadamer 1975:269). It moves fluidly as an accompaniment to one's view, inviting one to further advance (p.217), and represents the extension of vision required by one seeking to understand. The old adage 'to broaden one's horizons' involves a looking beyond what is immediately to hand in order to view it as part of a whole, and therefore in truer proportion (p.272).

### **Fusion of horizons**

With a new perspective gained, understanding takes place during an interaction, when another's horizon intersects - or fuses with - our own. Our range of vision is thus extended (Walsh 1996:235), and we might be heard to exclaim: 'I see!' The generating of such new understanding on both a personal and textual level is explicated hermeneutically by language. 'It is not only reason and thought which stand at the centre of philosophy', writes Gadamer (1996:165), 'but also language itself, the means through which everything comes to expression'. So rather than language being some commodity one possesses 'in the world', it is crucial to having a world at all (Gadamer 1975:401).

### **A life cycle**

Gadamer (1995:261) invites the inquirer into the hermeneutic circle, reverberating with Heidegger's notion, whilst elaborating upon it with the Husserlian 'fusion of horizons' concept. Meaning of the part is manifested from the whole, within the constantly expanding circle. Gadamer defines the circle by stating what it is not. By no means a formal methodological device nor structure, it is neither subjective nor objective. He sees it as a dynamic arena in which understanding is generated as the result of the 'interplay of the movement of tradition with the movement of the interpreter'. In contrast with Heidegger's work, Gadamer does not ascribe to Being

the source of truth. Residing not with the individual, it is determined by tradition. As the context of the past, a framer of the present, and a shaper of the future, tradition is the filter through which all meaning is drawn. Not some absorbed precondition, tradition emanates from within, informed by our culture, history and language (Geanellos 1998:160).

During conversation, understanding is drawn from the dialogue with the raconteur. Gadamer invests printed text, however, with an entity of its own, divorced from its author's meaning. This has implications for the research process and the role of participants. According to Gadamer's conjecture, having given their biographical accounts, the participants' contribution is complete, and the notion of revisiting them with transcripts for so-called verification is seemingly incongruous (Geanellos 1998:157). Interpretation is derived not from the author/raconteur, but from the text itself. The horizon of the interpreter becomes fused with that of the text by the dialogue of the former with the latter. Thus is released the potential for multiple interpretations of one text, with potentially as many understandings as there may be readers, because each brings to the reading their unique prejudices (Geanellos 1998:157).

A note of caution accompanies Gadamer's (1975:236) description of the process. He emphasises the necessity to focus on the phenomenon at the expense of any distracting preconceptions that the interpreter entertains. Reading involves looking for meaning in the text. Initial understanding is grasped and projected upon it, being revised as subsequent meanings emerge - and the reader's horizon expands. Several understandings can be conceptualised and held simultaneously until a unified meaning is derived.

Such discussion of the derivation of meaning precipitated my contemplating, as one purporting to understand the lived experience of the participants, where do I consider that understanding to lie? What do I consider its source and mode of extraction? With whom does it lay?

### **A clearer perspective**

It was when I came to phenomenology as espoused by Max van Manen that I moved beyond a somewhat detached sense of understanding where the previous authors I had read were coming from - or indeed, aiming for. Not only does he reiterate Heidegger's call to see research as a caring act, but I related to his imperative to live the question (van Manen 1990:43), because, upon reflection, I had, unwittingly, already begun to do so. It was my clinical relationship with families with CF that had caused me to conceive and enunciate my research question. Van Manen sees in phenomenology the potential for access to children's - and their families' - lifeworlds, which I was intending to do.

It was while studying teacher education in the Netherlands during the 1960's that van Manen became acquainted with phenomenology. The influence of the early phenomenologists is evidenced by his somewhat eclectic approach.

### **Phenomenology – what it is/what it isn't**

Describing phenomenology as a perspective not a method, a poetising activity, van Manen (1990:53) considers the lifeworld to be both source and object of phenomenological research. 'Phenomenology', he writes, 'merely shows us what various ranges of human experience, what worlds people inhabit, how their experience may be described, and how language (if we give it its full value) has powers to disclose the worlds in which we dwell ...' (van Manen 1996b:46). Investing language with such power, however, needs to be tempered with van Manen's own suggestion of its converse limitations. Conveyed experience is unique to the raconteur, and yet must be couched in common words. There exists, then, the potential for those finite units of speech to fail to fully explicate the unique and private qualities of inner experience. Are they beyond linguistic reach? Having teased the researcher with this thought, van Manen (1997:3) suggests that language rather creates and describes an inter-subjective world.

Van Manen (1997:3) speaks of an unbiased approach to the experience under consideration, having dislodged and confronted any unexamined assumptions, echoing Gadamer's highlighting of prejudice. In describing phenomenological reduction, he infers, however, that the researcher needs to overcome those feelings,

preferences or attitudes that would hinder the viewing of a phenomenon or experience (van Manen 1990:185). Rather, do not these constitute the horizon that will be involved in the interplay that is the fusion of horizons? (Maggs-Rapport 2000:373).

### **‘Carefully edified thought’**

Seeming loath to enumerate designated ‘steps to research’, van Manen (1990:30) prefers to ‘animate inventiveness and stimulate insight’. Like those describing phenomenology before him, he reiterates that there is no method, rather a perspective, and an understanding that comes by doing. Munhall (1994:169) advocates negotiating the research terrain ‘mapless.’ Van Manen’s (1990:164) suggestion that a ‘study of “the experience of a chronic life-threatening illness” may require the invention of a unique method’ rang with particular resonance for me.

With such intentions stated, van Manen (1990:30) then proffers the following, incongruously called, ‘Methodical Structure of Human Science Research’ - processes that are not necessarily chronological but rather synergistic.

The initial activity is the focusing on, and questioning of, the phenomenon that draws one into the research process in the first place - a ‘turning to the *nature* of lived experience’. It is that firstly noticing, and secondly, responding to, and seeking to make sense of, some aspect of human experience. This project represents just such an initiation. As a nurse who has cared extensively for families living with CF, I have taken, as it were, a step back from treatment regimes, hospitalisations - the extent of my professional view, or, after Gadamer - horizon - and asked: “But what *is* their experience?”

I have since deliberately taken steps forward - into their lifeworlds, seeking what might be their outlook on this phenomenon of life with CF, as I set about ‘investigating experience as we live it’. This process is achieved not by detached observation but by being immersed in the context - and standing in the ‘midst of the world of living relations and shared experiences’. I do this ever mindful of the uniqueness of each person’s experience, charged with van Manen’s caution that a phenomenological account represents but one interpretation, which is by no means exhaustive as equally valid and possibly more potent descriptions may await.

Thus immersed in stories shared and experiences brought to light, I, as researcher, begin to delve around for what it is that constitutes the nature of this thing - the daily living with CF, such consideration 'bringing into nearness that which tends to be obscure' in the process of 'reflecting on essential themes'. Within that process, however, some manifested meanings may not be unique to the phenomenon under investigation, being rather more incidental themes. So the researcher strives to explicate those themes that are essential, being aware that even these may not be free from historical or cultural influence (van Manen 1990:106). Theme is proposed by van Manen as a way of accessing the meaning of experience, as giving 'shape to the shapeless' (p.88) - something to hang it all on, being aware that no thematic device will render a total explication.

With phenomenon encountered and understandings apparent, the researcher moves into a phase of 'writing and rewriting' as language is used to render accessibility to the phenomenon by those who inquire of it (van Manen 1990:30). It is at this juncture that the researcher utilises the medium best suited to both the nature of the investigation and to their expressive abilities, in order to render the most profound exposé, and be acceptable in the milieu in which it is to be presented - in this case, an academic thesis. The research question under consideration here, however, would lend itself equally to portrayal in film, and expression in poetry or art.

Anticipating the pitfalls of engagement in the process of research in a somewhat unstructured format, van Manen (1990:31) cautions the explorer re 'maintaining a strong and orientated relation' to the question at hand, preventing them from becoming sidetracked in inane conjecture, blinded by preconceptions, or wrongly focused on self-centred reflection. Inherent in an orientated attitude is the danger of losing sight of the end of the research pursuit, which is the completion of a coherent résumé of the research project. One needs to be regularly stepping back in order to view the parts in context of the whole. There would seem to be, however, a fine balance between maintaining a focused execution without resorting to structured procedures - a harmony achieved by realising what van Manen (1990:34) dubs 'the spirit of this kind of inquiry'.

## **A 'write' approach**

Following my foray into the lifeworld of my participants via the interview process, I would reflect upon the experiences imparted to me. How would I to draw conscientiously from their stories, and represent a trustworthy rendition of the phenomenon?

Preset patterns for presenting research, according to van Manen, (1990:167) may not always be interesting or insightful. Rather than a structured outline, such as a predefined table of contents, he directs the researcher to five possibilities for dealing with the writing process - thematically, analytically, exemplificatively, exegetically, existentially or an invented approach (p.168). He would say that this is no itemised list, but rather suggested springboards to understanding, derivations of which could be blended together. Conversely, he issues the challenge to researchers to devise their own approach, one option I considered as I explored his suggestions, mindful of his exhortation that the phenomenological researcher needs to be reflective, insightful, sensitive to language, and constantly open to experience (p:6).

As one gathers the participants' contributions, it is not long before recurrent themes become apparent, as does the efficacy of extracting them and utilising them as points upon which to hang the analysis. Such isolating of themes can prove difficult, as one will of necessity flow into another.

Alternatively, van Manen suggests an analytical application to the data at hand, describing three different ways. His first suggestion is the writing of narratives drawn from the participants' life stories, anecdotes they have relayed, or even the creation of a fictional account; the process being completed by thematic examination. Secondly, one particular occurrence may be described to set the stage for the inquiry. Thirdly, describing how the phenomena is currently understood and portrayed, or, conversely, overlooked, will highlight the need to investigate it and will provide the contrast against which understanding is revealed.

The researcher may endeavour to present a clear picture of a phenomenon exemplificatively by initially describing it and then utilising diverse examples of it. Each illustration serves to highlight one of its particular facets.

By drawing upon the commentaries proffered by recognised phenomenologists, the researcher can exegetically utilise the platform of traditional writings to inform their description, reflectively enhancing it with their own lived experience.

Finally, van Manen (1990:101) considers approaching participants' narratives existentially. As a guide, he suggests four existentials, which are both generic and pervasive in lived experience regardless of historic, cultural or social context. A summary of these four areas will give insight into the potential they have for bringing to clarity the phenomenon of living with CF, and thus my decision to utilise them. In this study, they will form, as it were, a cyclorama against which the action of play is accentuated, each of the four facets of experience illuminating the action with a unique hue. So that you the reader can fully appreciate these dynamics, I will relate them to *you*, so that your comprehension might be experiential.

#### **Four lifeworld existentials**

As you read this, you are most probably not aware of being in 'lived space (spatiality)', particularly if you are seated comfortably in the familiar surroundings of your home or office. If, on the other hand, you are in a more public arena, such as a library, you may be conscious of its vastness, possibly aware that someone has sat on a seat close to you, invading your personal space, or, indeed, spread their study materials so that they are encroaching on an area that although unstated is designated as yours. So the notion of space under consideration in this existential is not that of measurable, actuated space, but rather that which is perceived and is therefore largely preverbal.

When doing an oral presentation, I am acutely aware of moving from the safe space of sitting amongst peers, to that very public area at the front, which seems an inordinately long way from my seat. A person confronted by a large institutional building - a hospital, for example - may feel overwhelmed by being in space that is unfamiliar, an important consideration in the lives of children subjected to it.

To continue the analogy of my presenting a paper, as I stand in front of the assembled group, I become acutely aware that all eyes are potentially on me, and I am conscious of how I am standing. Is my nervous twitch obvious? Can they see past me to the

overhead screen? Although my mind has conceived the concept to be presented, it is delivered through the medium of my body. One is always bodily in the world, and this consideration of the 'lived body space (corporeality)' is essential in the explication of lived phenomena, its inclusion in a study on CF being patently obvious.

As I continue with my presentation, you may be plunged into consideration of 'lived time (temporality)', either because it is riveting or amusing, and is over in no time. Conversely, it may be tedious and you are painfully aware of time passing very slowly indeed, prompting you to look at your watch to quantify for you how your subjective perception of the time matches up with that displayed objectively by your timepiece.

Another facet of this notion of time is that of past, present and future - one's temporal landscape. For families living with CF, some periods of their life are elongated, reflected in such comments as "it felt like forever, the just waiting", in reference to diagnosis; or conversely, of future time, which is moderated and designated finality by, most often, a doctor's prophetic words.

Thus clad in bodily form, an occupier of relative time and space, we inhabit a world in which, generally speaking, we encounter others, in a myriad of relational interactions with a 'lived other (relationality)'. To return to the example of my presentation, an audience is assumed - a group of people who, as each arrived, would have related to each other either with a smile or nod, possibly a handshake; maybe an effort at avoidance in some cases - but whatever the response, an acknowledgment of the other's presence bodily. What might be the impact upon those who live with CF in the arena of interpersonal relationship?

Although I have discussed these four existentials in neat compartments, they are manifested inter connectedly in an individual's lifeworld, being distinctive for each person, with children having a different, evolving interconnectedness with their world (van Manen 1990:101). Their suitability and efficacy for a study such as this is clear, and thus, this research project is framed with the work of van Manen.



## Tree of life

Upon entering the field, the novice reader of phenomenology is soon faced with a juncture at which they are presented with divergent ways in which phenomenological insights are gained. As with many movements, those who have been central to its conceptualisation tend to see only from whence it has come, and the destination at which they would like it to arrive. It is commentators with the advantage of an overall retrospective look who are able to plot its developmental milestones. Phenomenology has been subjected to just such delineation. After much contemplation, the writings of its progenitors settle into a strikingly neat pattern in which the inaugural body of phenomenology then gives rise to distinct branches, its analogy with a tree being not only striking but also eminently suitable for a philosophy that seeks to portray life.

It was the seeds of doubt regarding the current thought of his day that planted the germ of the new movement in Husserl's mind. His descriptive phenomenology has been the solid trunk from which quite distinct branches have blossomed. He aptly claims:

Philosophy can take root only in radical reflection upon the meaning and possibility of its own scheme. Through such reflection it must in the very first place and through its own activity take possession of the absolute ground of pure preconceptual experience, which is its own proper reserve. (Husserl 1931:27)

Germany of the 1920's saw the flourishing of realistic phenomenology, which focused on the quest for universal essences of human phenomena, while the hallmark of constitutive phenomenology is the promotion of reflection upon transcendental phenomenological method, particularly *epoché* and reduction. Based on Heidegger's *Being and Time*, existential phenomenology gathered momentum in the France of the 1940's and 50's. It was fostered by Marcel, who pondered the mystery of Being; de Beauvoir, who considered gender and aging; Merleau-Ponty, who utilised Gestalt psychology in his understanding of perception and the lived body; and Sartre, for whom freedom and literature were the focuses of his work (Embree 2000:4).

A further offshoot has been the hermeneutic phenomenological movement, which may be considered a branch of its own. Embraced by North America in the 1970's and 80's, it proffers not so much varied philosophical trends, but rather a specific mode of interpretation - hermeneutics. Some phenomenologists, such as Colaizzi, van

Kaam and Giorgi actually prescribe recipe-like plans for executing research (Crotty 1996:22).

### *Comme il faut*

It is not possible to continue the arboreal analogy without encountering controversy as to which way the phenomenological movement has grown. If Crotty's (1996:2) perspective is legitimate, then the phenomenology thus acculturated by the Americans was not a transplant of the parent European plant, but a grafting in of local stock, manifesting in a crop reminiscent of American culture and its prevailing psychology.

Embraced by nurse researchers as a viable means of accessing the lifeworlds of those in their care, it also offered a way into the academic arena in which the then emerging discipline was finding its feet. Crotty nominates this phenomenology 'new', and conveys that it is almost errant in its quest to understand people's subjective experience. He places it in contrast with 'mainstream' phenomenology, which is objective in its goal to delineate not only the meaning but the phenomenon to which it is attached, drawing upon pre-reflective experience. This discussion is raised early on in his book *Phenomenology and Nursing Research*, a valuable resource and exhaustive text on the one hand; but one that comments throughout as to where nurses have seemingly erred in their appropriation of methods phenomenological. Charging them with misrepresenting the original tenets of its founders, he depicts nurses as not realising what they have left undone, as they have, he would suggest, created their own diluted counterfeit. His desire to maintain all things phenomenologically pure is noble; but if it has been adapted, evolved, modified and its efficacy as a research endeavour agreed, one is led to ask what the problem might be. What, in fact, would phenomenology be had antecedent branches not sprouted from the pruning by its founders?

It would seem that phenomenology 'as currently practised is no longer pure' (Johnson et al. 2001:246). Did not Heidegger draw from Husserl's project and embellish it? Were other growth rings - such as Merleau-Ponty and Sartre's interpretations - the subject of controversy and debate? The alternative is the notion of ring-barking the tree, but one wonders what heights and innovative shapes might be missed.

Caelli (2000:367) would absolve nurses from the charge of misconduct of phenomenological research, suggesting that American philosophy, having been, as Crotty writes, grafted on, has generated this evolutionary adaptation of the species. Enunciating the subtle difference between European and American phenomenology, Caelli invests the latter with great potential for extending the former, particularly for the benefit of the health sciences. Concurring with Crotty's summation of the differences - traditional phenomenology examining pre-reflective experience whilst the newer American explores the experience itself - Caelli sees no reason why the two cannot be harmoniously employed. Thus participant's personal experiences would help to decipher just what the phenomenon might look like. If a phenomenon is to be explored, then do it in every way possible.

One can appreciate Crotty's desire for Heidegger to, as it were, get a sound hearing; or rather, a legitimate reading, which even his fellow countrymen have struggled to do. So is it a case of something lost in the translation (and subsequent readings), or, conversely, added by default to enhance the original? One wonders what Heidegger would think - he whose work has been subjected to many and various interpretations (Johnson et al. 2001:246). Is it permissible to 'hear another refrain amid the notes?' (Wood 1993:146).

At this point of the discussion it is appropriate to add Darbyshire's (Darbyshire et al.1998) voice to the debate. As an integral player in both the phenomenological and the Australian nursing research milieu, how does he respond to the dispute over a traditional, objective approach to phenomenology versus a more subjective understanding? It is certainly a gauntlet that could not be bypassed. According to Smith (1998:926), it was 'with obvious fire in his belly' that Darbyshire delivered an impressive international conference presentation on the topic, substantiated with an apparently controversial use of the literature as well as an emotive critique. Such accolades sent me in search of the paper, prepared in collaboration with Diekelmann and Diekelmann (Darbyshire et al.1998), which describes Crotty's treatise as 'misguided' in some places and 'poorly informed', even 'vague' in others. By highlighting various aspects of Crotty's conjecture and his interpretation of Heidegger's work, they accentuate the fact that he presents what he considers to be 'actually' said in *Being and Time*. Darbyshire et al. (1998), however,

would suggest that in certain circumstances, there may be no 'single, *correct* interpretation'; rather more valid interpretations being retrieved by approaching the text as 'discourse rather than as an either-or dialectic' (p.21). Or is it a case of, as Crotty (1997:89) offers the reader, derive new meanings if you must, just do not say it is Heideggerian? Might it be not a matter of misrepresentation, but rather the conception of new ways of harnessing phenomenological philosophy to the inquiry process, reflecting choices both philosophical and methodological that researchers have made (Caelli 2000:368)?

The manner in which nursing has located tradition and culture in phenomenology's framework is a key area of dispute. Polarising the problem as arising from 'pro-culture' and 'anti-culture' readings of Heidegger's text, Crotty (1997:89) considers that many nurse researchers have erred by passively embracing culture and drawing understanding from it. Darbyshire et al. (1999:18) would decry this stance as being antithetical to the actuality of how nurses have rigorously questioned taken-for-granted understandings. Has Crotty erred by 'reading Heidegger as a complete iconoclast, intent on an entirely negative and destructive debunking of tradition' (p.18)? Such was never Heidegger's intention, deduce Darbyshire et al. (1998), suggesting that rather, he sought the revelation of tradition being camouflaged in Western thought (p.19).

It is with a note of gratitude that Darbyshire et al. (1998:17) acknowledge the contribution that Crotty's critique has made to nursing scholarship, regretting that his death has robbed the argument of a provocative, albeit supposedly 'misguided', voice. His legacy of debate amongst nurse researchers has fostered a consideration of just how are nurses doing phenomenological research, is it sound, and is it where we want to go? Is it time for another graft? If so, what might we like that to be? Is Heidegger's project to be thwarted - or redefined?

### **A new millennium**

This chapter opened in the late nineteenth century, and has pursued the evolutionary trail of phenomenology through the twentieth century, which closed with the fourth, hermeneutic period. My philosophical explorations have led me through settings German, French, American and Australian, pursuing information and a trail of

development that has flowed over continents. It begs me to ask: where is phenomenology headed? What will the phenomenology of this, the twenty-first century, look like? Embree (2000:5) envisages a fifth, planetary phenomenology, born of increased international travel and Internet communication. Nurse researchers have the choice to either take their hands off and let it grow wild, or actively sow into its shaping.

### **An envoy**

And what of Husserl? Would he be 'turning in his grave', or chuffed that his philosophical response to the Enlightenment movement and its proponents has spanned further horizons than any of their innovative telescopes would ever have dared to consider?

### **A starting point**

Thus was my understanding of phenomenology enhanced, although by no means completely because my reading had left me with a sense of 'all will be revealed.' My impression of phenomenology was an horizon that would widen as I actually proceeded to investigate the experience as lived (van Manen 1990:31) - rather than as I might conceive it to be.

As I had followed the progress of phenomenology from philosophical movement to research approach, and to nursing research methodology, I had been reading with several intentions. Firstly, I was seeking to understand phenomenology in order to assess its efficacy as the means by which to explore my research query. Secondly, I read with an attitude of which author's approach most resonated with my research intent.

Van Manen (1996a:369) considers:

The researcher is an author who writes from the midst of life experience where meanings resonate and reverberate with reflective being. The researcher-as-author is challenged to construct a phenomenological text that possesses concreteness, evocativeness, intensity, tone, and epiphany.

I related to this epistemological intent, and found that my query of: "What is the experience of living with cystic fibrosis?" sat well within it. My endeavours would be

well served by posing it from within such a framework. The following chapter outlines the methods by which I have done so.

## **Preliminary processes**

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Having decided upon the particular philosophical filter through which I would view the participants' accounts, I was conscious that such a stance requires the following of specific, prescribed steps to permit access to this lived experience. I will now detail the methods used, in order to explicate the research process and to make patent the research trail through which it passed.

### **Ethical matters**

One is not too far along in exploring the field before one must negotiate the fact that there is 'no entry without permission', and that access will be allowed only when intentions are clearly enunciated, understanding of appropriate safeguards established, and insight into repercussions demonstrated - via the Ethics Proposal. I was required to gain such approval from the Ethics Committees of both the University of Tasmania and a local hospital, the latter because I planned to make initial contact with my participants via the CF outpatient clinic convened there.

I was asked to present my research proposal to the weekly meeting of the hospital's paediatric department - a multidisciplinary forum which encompasses such activities as the outpatient clinic. This provided an opportunity to detail formally the how and why of my project, which involved children and families that many of this team had cared for since diagnosis.

### ***Modus operandi***

I envisaged that the registered nurse who conducted the CF clinics - my colleague Nicola - could act in a gate-keeping role, making the initial mention of the research project to prospective participants. She would ask whether or not they would like to meet me, giving them a very clear indication that such an introduction was by no means obligatory, nor was their accepting or declining in any way connected with their - or their child's - future treatment. Thus they were free to say yes or no to

Nicola, within the context of an already established relational trust, alleviating what can be an inverted power play when one - 'researcher with badge' - can unwittingly engender compulsion to comply in the other - parent or child in unfamiliar territory. In establishing the guidelines for the project, I was acutely aware of protecting these families' privacy and option not to participate, being only too aware from both personal experience and reading of the literature that for most of their child's life, the intimacy of the family circle has been invaded and altered, not only by the disease, but also by those who seek to assist in the alleviation of its effects.

I did, however, underestimate their unanimously affirmative response - in some cases delight - to my suggestion of "this is your opportunity to tell your story, to have your say." For, while they may have responded through years of valid and informative questionnaires, for which they were used to proffering pat, treatment-orientated answers, there had not always been a space for their response to "how has it been for you?" Pre-empting that there was absolutely no compulsion applied, I extended the invitation to include their child, and described what format that contribution may take - drawing or talking.

I then furnished them with an Information Sheet [Appendix 1] written in an easy-access question-and-answer format. Explaining that I would call them at home within the next few days, I asked them to tell me their phone number. Thus they permitted me access to them by phone, and this also served to emphasise tangibly that I was not consulting their medical files for personal details. I terminated the initial encounter without continued chatting, being aware that they could start there and then to delve into their cache of stored experience - as, indeed some started to do. In the spirit of true phenomenology, I was keen to capture their recollections before they had an opportunity to reflect upon them. It would be ideal to meet participants initially with tape-recorder at the ready and invite them to talk. But such are the constraints of the ethics process, which protects not only vulnerable participants, but also the researcher, and on both counts I was only too keen to abide.

Thinking I was allowing people thus contacted some time to peruse the Information Sheet and consider participation before I phoned them, I was greeted by two parents who were wondering where I was. One mother said: "The answering machine



activated but there was no message - I thought maybe it was you.” Another simply jumped immediately in with: “Yes. When?”

### **A child's eye view**

Until recent years, a notably absent voice in studies of CF has been that of children, their interests being served by the dominant adult ‘non-confused’ voice (Sartain 2000:920). Relegated to the role of passive objects of study (Nespor 1998:370), children's unique perspective and insight on their condition have not often been sought, and a valuable source of information and useful data left untapped (Ireland & Holloway 1996:155). It has been assumed by adults who have nominated themselves the interpreters and translators of the child's world (Waksler 1986:73), and arbiters of what is best for the child (Ireland & Holloway 1996:159). While adults have had children's best interests at heart, they may have, in their protective altruism, not fully grasped what those interests might be.

Darbyshire et al. (2001:191) highlight a reluctance of researchers to interact directly with children. Such reluctance arises from a particular view of childhood and children's assumed capacity, their immaturity rendering them awkward, as far as research anyway. Rather than considering the deficit notion of ‘less’ than adults, Waskler (1986:74) suggests ‘different’ as being a more legitimate descriptor for children's knowledge and experience, the former a notion of judgement, the latter a focus for research. Waksler (1986:72) conjectures that socialisation may actually entail not children becoming adult but rather children learning to act like adults, rendering adulthood a tenuous achievement requiring continuous accomplishment. She suggests that the assessment of children according to deficit categories - pre-cognitive, non-verbal - portrays them as lacking and in a constant state of being prior to achievement. Likewise the bias towards considering them to be in error and lacking understanding, such as in their utilising language differently from adults, leads to the presumption that they are incompetent to convey their experiences. Curtis (1978:xxiii) recommends finding out from children how they are using words. Their lively imaginations and use of rich imagery do not detract from accuracy, but confirm it (Ireland & Holloway 1996:162).

## **Parental guidance**

Preliminary considerations of this study centred around who I would engage in the telling of the CF experience. To have just the rendition by the child would present only part of the story, because the life with CF begins before the child could recall - or was even born in some accounts. Thus I have included the version as viewed through the parental lens. Parents are there from the beginning. They are the framers of the child's world, as well as guardians and negotiators within it. An exploration of the lifeworld moderated by CF should consider the nature of the unique parent/child relationship that is fostered when a chronic, life threatening illness informs the interplay.

Because of this focus, brothers and sisters are not included. While they are essential members of the family, their relationships with their parents and their sibling are distinctive ones, warranting a separate study of this potentially vast subject.

## **Just a stage**

While endowing the parents in this study with one homogenous status - adult - I nominated to interview children across the childhood age-span in order to gain understanding of the phenomenon. Subtly attendant to this is the concept of 'ages and stages'. In the context of a phenomenological study, it seemed incongruous to deal with half the participants in such a structured manner.

It has been the literal acceptance of Piaget's prescriptive timetable that has led to the presumption of difference in the understanding of adults and children (Ireland & Holloway 1996:160). By emphasising cognitive capacity, Piagetian theory suggests that understanding in one cognitive area will be commensurate with that in others (Crisp et al. 1996:58).

Some commentators now describe development occurring via a series of 'novice-expert shifts' (Crisp et al. 1996:59, Eiser 1989:96), such expertise theories allowing for variations in understanding according to experience in a particular domain (Crisp et al. 1996:58). A cognitive structure is inadequate in accounting for children's perceptions of their illness, adds Eiser (1993:26), suggesting an alternative focus on their social context as a determinant of their experience, a model that is not static

because of its reflection of the natural transitions and changes of childhood (Eiser 1993.28).

The move away from the adherence to cognitive stages has seen a correlating recognition of the pertinent contribution children can make to the research of which they are beneficiaries. Hence their participation in this study, as unique contributors, via a variety of expressive mediums - talking, drawing and poetry.

### **Meeting the criteria**

While I was not slotting children's contributions within the structure of 'ages and stages', I planned to garner experience across the developing life span through to adulthood. As a consequence, the participants' contributions reflect the developing history of CF treatment and prognosis.

In consultation with Nicola, and with her generously proffered support and commitment to the process, I was ushered into lifeworlds of the following group of people. They are represented by numbers and pseudonyms at this point but will be introduced fully in the proceeding chapter.

## Table of participants

(non-participants are displayed in parenthesis)

| Child with CF | Age | Sibship position | Mother   | Father    | Step parent | Sibling            |
|---------------|-----|------------------|----------|-----------|-------------|--------------------|
| Mark          | 2   |                  | Dianne   | (Philip)  |             | (Alex)             |
| Grace         | 4   | 1st              | Cathy    | Brad      |             | (Bronte)           |
| Toby          | 5   | sole             | Kim      | Pete      |             |                    |
| Max           | 7   | 3 <sup>rd</sup>  | Julie    | (Neville) |             | (Cindy)            |
| Ian           | 13  | 2nd              |          |           |             |                    |
| Brooke        | 8   | 1st              | Liz      | (Garry)   |             | (Adam)             |
| Hannah        | 13  | 3rd              | (Louise) | Ross      |             | (Chris)<br>(Donna) |
| Bob           | 18  | 1st              | Clare    | Nigel     |             | (Brie)<br>(Lucy)   |
| Tim           | 21  | 1st              | Ann      | Brian     | Stuart      | (Ryan)<br>(Dylan)  |

### **A risky business**

I have had experience researching with parents of hospitalised children who all attained a complete recovery (Jessup 1999). While the illness experience had been traumatic for those parents, they were able to recount it to me as an isolated incident from which their child had, physically anyway, recovered. When considering interviewing families with CF, and all its attendant known traumas and unknown outcomes, I perceived that these interview sessions could be potentially distressing for them, particularly when participants have an opportunity to verbalise for the first time issues and emotions that they may have held unrealised.

Such an outcome was by no means daunting for me, as my accrued years of 'people experience' as both a nurse and a crisis phone councillor, meant that I was *au fait* with the appropriate response to any distress that may have been beyond the bounds of a research interview. In preparation for any such eventuality, I discussed my research project with the social work department of the local hospital. I appreciated their willingness to be available should they be required, not only in cases of distress, but also in the event of any other issues raised that required follow-up.

### **My vantage point**

In turning to this phenomenon of living with CF, my orientation towards it has been from, as van Manen (1990:40) describes, a certain vantage point. While I share his particular interest in children, his stated professional stance is pedagogical, while mine is that of nurse. Such professional focus aside, I come, like van Manen, to the research question at hand with the attendant role of parent of two sons, and being one for whom friendship and personal interaction is a priority. The sum total of those human dimensions of my life is fused into the lenses of pre-understandings and, I have no doubt, presumptions, that have constantly accompanied me through the research process. These have no doubt been fortified by my snippets of contact with CF families and my previous research experience with parents of hospitalised children. I have accrued, as it were, a selection of souvenir snapshots, whose borders render the finiteness of freeze-framed time and a guessed-at context. The deep interest that has brought me to, and now directs, this research endeavour, is my desire to now see the full-length movie - a panoramic view laden with sounds.

Being acquainted with many of the participants through my nursing role meant that to these families I needed no introduction. This greatly facilitated the rapport-building process, as within the comfortableness that that afforded was a foundation upon which they could immediately begin to lay out their experience. Conversely, this familiarity sometimes exhibited a different effect upon the interview process as it adversely tainted their telling with a medical focus. Over the years, they were mostly interviewed regarding this, and they assumed that, as a nurse, was that not what I wanted to hear? During some interviews, I needed to gently coax the participant out from behind the lineal description of, for example, medical routines or surgical trauma, with a: "How was that for you?" - but ever mindful that such medical rigmarole is intrinsic to their life world.

### **A suitable setting**

A crucial factor in facilitating this interview flow was the setting. By my coming into the interviewee's home space, any notions of clinical context or interrogation were, to a large extent, dispelled, and they assumed a sense of control over the environment (Ireland & Holloway 1996:158). Children were in their familiar surroundings and responded with a sense of: "If it's alright with Mum, it's alright with me."

### **Interviews**

My previous research experience with families meant that I felt quite comfortable in that situation, setting the tone for unstructured, conversational-style interviews (van Manen 1990:66). Once they got a flow going, however, my contribution became the intermittent interjection of "uh-huh" and acquiescing head nods, as I actively listened.

Even though participants had been furnished with the Information Sheet [Appendix I], I reiterated its contents verbally before starting. Thus I reminded them that they would be taped, and ensured that they understood not only the implications of the Consent Form [Appendix 2], pseudonyms and anonymity, but also their prerogative to decline to proceed with any response, or, indeed, with the interview in general. Likewise, their child was not to be coerced to contribute beyond their wishes - a notion generally administered by the parent, except if it was clear that they wanted the child to fulfil my expectations by participating or continuing, in which case I took the initiative to relieve them of that obligation. Who went first and who was present had

sometimes been predetermined by the family, while at some of the interviews this was decided collaboratively with me, and occasionally was a sort of melee as excited little ones assigned to play quietly in an adjoining area could contain their inquisitiveness no more.

Generally, younger children were happy to either draw and chat, or draw first, explain later. A hiccough at the closure of several sessions was ownership of drawings. Now the parents and I assumed that the children would naturally give me the drawings whose execution had been directed conversationally towards me. However, on several occasions, the young artists were keen to give their creations to a parent, ostensibly for display on the refrigerator gallery. In those cases, parents took the initiative and encouraged the child to allow me the privilege of taking the special drawing home.

### **Transcribers**

Interview tapes were transcribed by two women with a particular interest in children and families, not only personally as parents, but also professionally - one in the area of education and the other as a midwife. Now while proficient, professional transcribers can perform their task at such speed that details of the contents may elude them, my colleagues work at a pace that permitted them to comprehend the stories emanating from their headphones, perhaps even slowing at more salient moments of the accounts. Thus, upon breezing in one day to collect their work, I encountered them seated ready for coffee and a debrief cum feedback in response to the impact that these phenomenological pieces had had.

Their responses were mostly questions of 'what about this?' and 'what about that?' While some of the participants' experiences were not totally unfamiliar to me, they were stark for these women, whose awareness and queries highlighted some of the more extraordinary aspects of living with CF. This encounter informed my presentation of the analysis because it gave me further insight into what people might want to know in order to enhance their understanding of the phenomenon.

### **A word in confidence**

Notions of anonymity being conferred by a change of name is standard research practice and a great idea in theory. Such has been the case, however, that some participants - particularly the young adults - could be identified in certain circles, a common occurrence in a smaller state. By utilising every means possible, I have striven to render anonymity to the participants, but it is difficult to disguise, for example, a twenty-one year old young man who has undergone lung transplantation; a notion of which he was calculatedly aware when he consented to share his story. Since his surgery, he has adopted a somewhat public profile, speaking openly about his experiences at various forums.

Several participants disclosed personal information that was not only distinctive but that could have a potentially harmful impact upon others who may read it. In order to protect their anonymity and personal integrity, details of this nature have been deleted, albeit not without affecting their narrative, it being part of the life they are living with CF.

### **Dealing with data**

Being somewhat loath to designate as 'data' the rich tales conveyed to me, I was intrigued to read that van Manen (1990:53) divests the term of its association with collected objective results by suggesting that a similar process of garnering has occurred in human science research, only in this instance the 'data' are human experiences (p.63). By considering its origin - 'datum' - meaning 'given' or 'granted', the notion is conveyed that life endows experience (p.54); its Latin derivation - '*dare*' - meaning 'give' (Concise Oxford Dictionary).

So there has not been a sorting of data as such, the process of explicating the phenomenon under question actually beginning as I imbibed its initial recounting. By the subsequent reading and rereading of transcripts, listening again to the tapes to verify and to recall subtle nuances, I have allowed the text to speak through these interactions, in a continual turning from the word spoken to the context in not so much an automatic action, but rather through the fine attuning of a hermeneutic attitude (Walsh 1996:235). Aware of the barriers that pre-understandings can create, I



have taken account of these and striven to interrogate the data from new and varied perspectives (Wiklund et al. 2002:114).

By situating the lifeworld dramas before the cyclorama of the four existential themes expounded by van Manen (1990:101) and enumerated in the preceding chapter, a clarity came - not unlike a photographic image appearing in a darkroom solution - and the phenomena I have been investigating began to materialise. I then proceeded to write descriptively, my aim being that you, the reader, will also grasp its manifestation. Hence the expose' that is the following data chapters, culminating in the thesis that is the heart of this research endeavour.

### **Held in trust: rigorous debate**

The investigator has not long embarked upon the research path before needing to demonstrate that the study is executed in a sound and trustworthy manner - the concept of rigor. Husserl's (1917:10) declaration that phenomenology is 'inferior in methodological rigor to none of the modern sciences' leads to the query of how has his statement stood the test of time? Not only conferring his philosophy with the title 'science', he committed it to justifying its process. Heidegger (1962:195) writes that 'mathematics is not more rigorous than historiology, but only narrower, because the existential foundations relevant for it lie within a narrower range'. Thus from its inception, phenomenology has been framed with nomenclature that would seem to belong to a differing mode of inquiry.

In their attempts at conformity, nurse researchers in the eighties embraced the scope offered by phenomenology on the one hand, while continuing to not only invoke the concept of rigor, but also conferring upon it the legacy of their medical science roots, wherein 'proof' is required (Jasper 1994:313). Seeking understanding is not some evidence-producing exercise in confirmation, writes Munhall (1994:84). She emphasises that the study of experience is 'not to substantiate our perceptions'. Rather this study might even 'liberate us from our preconceptions'.

The notion of verification implies the existence of some objective truth out there, masquerading as data, such a concept rendering knowledge static and complete

(Geanellos 1998:156). Thus the often-espoused process of achieving credibility in qualitative research by the auto-validating of participant's contributions stands in stark contrast to that paradigm's concept of an evolving knowledge. A Gadamerian perspective, on the other hand, confers ownership of meaning to the text rather than the raconteur (p.157).

Picking up the rigor debate in response to criticisms of the human sciences being less rigorous than their quantitative counterparts, van Manen (1990:15) describes them as rather appearing undisciplined by comparison because of their seeming ambiguities, unmeasured data, and lack of replication, the only form of generalisation allowed in phenomenology being to *not* generalise (p.22). Viewing human science within its own criteria reveals a notion of rigor wherein the aim is a precise and complete description (p.17).

Darbyshire (1992:63) writes of the 'complexity and fluidity of social life and of the presence and effect which the researcher has upon every element of the study', dynamics which obviously cannot be poured into a structured mould of generalisability or reliability. We are not aiming for generalisability, Koch (1998:1186) would say, but rather, a new or better understanding is sought. It is a looking beyond the typical to regard the particular, such a view enhanced by Fitzgerald's (1995:2) comment that there is no such thing as a generic chronically ill person. How could I be satisfied that my research project was a trustworthy one?

### **Follow the signs**

After reading Koch's (1998:1188) work, which draws on that of Guba and Lincoln (1989), I considered my project in light of credibility, dependability and transferability. Creditability is the result of aiming to present such a faithful interpretation of a human experience that anyone having that same experience would recognise it. Dependability means that a reader or another researcher could clearly recognise and follow the 'decision trail' I have blazed, and arrive at similar understanding. Transferability implies a potential degree of similarity between two contexts.

Further verification for this project came via several presentations during its execution. Delegates at an international paediatric nurses conference responded knowingly to this project, while those at a national conference for CF nurses rendered it confirmable with some very understanding phenomenological nods. The participants' contributions, and my analysis of them, resonated with clinicians' experience, while also enlarging their understanding of the phenomenon.

Koch (1998:1184) emphasises the central place reflexivity should occupy in the whole process, a practice in which I have partaken by virtue of keeping a research journal, a formalising of the reflection in which I was naturally engaging anyway. While some entries have been practical jottings, others record some of my initial responses, such as the following:

*That feeling - when they open the door. Today she took so long, I started to doubt - started to think: "She's gone out because she doesn't want to talk after all." Funny when they think that they won't know what to say - will need me to ask questions, but then, after a few hesitant sentences, maybe even just one, they tap into an utter torrent of pent-up experience, narration, reflection, shared memoirs, emotions and previously unconsidered, undivulged anecdotes.*

*When having copiously thanked them, acknowledged their contribution and bade them farewell, I am alone again in front of their house, having entered their world, now preparing for re-entry into mine, so conscious of the precious jewels they have entrusted to me - their lives enfolded into cheap cassette tapes, deemed anonymous and confidential on a wordy consent form, but I am so aware of the privilege, the responsibility to handle the contents as delicately as if the heart they have shared with me were an actual organ to be transplanted. Deal with it correctly, or the potential for it to endow further life will be lost (Jessup 2003, unpublished journal).*

### **From process to participation**

So, with methodological tenets made patent and procedures described, it is now appropriate to 'bring on the participants.'

Let me introduce them to you.

## Prose, poetry and pictures: data disclosed

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### Putting it into context

Dubbing them 'co-investigators' rather than 'interviewees', van Manen (1990:98) comments that participants in a study have a propensity to invest more than just a passing interest in it. He likens the process to talking with friends.

The importance of the situated context cannot be overestimated, stresses Munhall (1994:84). Thus you, the reader, will be privy to this from the outset, in order that your responsive reading of the data (van Manen 1990:130) be enhanced, and your following of the research trail facilitated. By my describing the interview contexts, you gain a further entrance into the participant's lifeworlds that goes beyond the numerical summation of age or number of family members, and the explication of the phenomenon begins.

Van Manen (1990:125) points out that whatever the research paradigm, there comes the time for committing the process and data to a written report. He cautions, however, against pursuing conventional methodological rigour and conformity at the expense of realising the potential of writing as a poetic textual understanding, capable of divulging deeper insights than more traditional structures may allow. Barthes (1986:318) considers that the demand for rigorous formality, wherein method takes precedence over writing, results in a sterility concluding that there is 'no surer way to kill a piece of research'.

### A certain style

The object of the research process is to create a phenomenological text (van Manen 1990:111) wherein the significance and meaning of the lived experience are conveyed by not only the identification of appropriate themes, but also their illustration by exemplary description (p.122). When such a study is truly a contribution, an audience will be moved by the description, being affected by the descriptive words - whether or not they have personally had the experience, writes Munhall (1994:51). Echoing

Barthes (1986:318), she adds that to place such a study within the academic format potentially removes its lifeblood. Munhall (1994:115) commends utilising sources often considered 'anti-method' - those artistic sources such as photography, film and literature - that have been excluded from scientific inquiry.

Academia would aspire to innovative research design and a unique contribution to current knowledge. There exists, however, the subliminal assumption that a research report should sit within a stable structure, display expected features and be couched in a certain genre in which the researcher is either subsumed behind the third personal pronoun, or constrained by customary modalities of expression. I confronted this wall early on in the rendering of this thesis. Tension arose as I sought to comply by compressing the candid, colloquial stories from research participants into a detached language. This seemed not only to limit and prune their vivacity, but also to detract from the overall bearing that research with children and their families naturally brings.

On the issue of narrative framing, Barone (2001:171) aims to provide 'textual breathing space' by refusing to drown fragments of a participant's account in a 'sea of scholarly prose'. He refers to theorists who consider the placing of a 'vernacular, literary, anecdotal, narrative portrait into a paradigmatic envelope' to be not only demeaning to the storyteller, but also rendering them violence through this 'academic arrogance' (p.170).

This is a notion that Madjar (1991:105) has obviously confronted in her doctoral study of the phenomenon of pain, and I related to her disclosure of the tension that is generated by the demands of phenomenological writing on the one hand, and academic conventions on the other. She alludes to adjustments that she made in order to meet expectations without losing the phenomenological potential.

This research project represents a collection of participants' personal narratives - spoken contributions, poetic expressions and felt pen drawings - all of which will be described with the brushstrokes of the descriptive mot, and synthesised into as true a portrayal of the lived experience of CF as such subjective vehicles can do. My intent is that you will, to reiterate Vezeau (1994:169), smell the smells and feel the full impact of the experience of living with CF.

## Tim

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The blood in the bottle had already dropped by more than half. It had once flowed in someone else's body, a body with its own personality, its own ideas, and now it was pouring into him, a reddish-brown stream of health. Surely it must be bringing some of its own characteristics?

Alexander Solzhenitsyn, *Cancer Ward, Part II*

I'm driving but stop to check the address slip again. For while my destination is totally unfamiliar, the person waiting there is not. I am off to visit my first research participant, who is house-sitting this week. My trusty tape-recorder, twice checked, and battery supply, likewise accounted for, lie incongruously on the seat. How out of place they seem when I feel as though I am going to drop in on a friend - because I am certainly acquainted with this twenty one year old man. 'Known to the ward' always pre-empts his medical notes, like he has had some previous sentence. It is five years since I met him, and I have witnessed his gradual deterioration, until the theoretical concept of lung transplantation became a reality twelve months ago.

Thus endowed with substantial foreknowledge and pre-understandings, I ring the doorbell, suddenly conscious that those advance insights are but a temporary horizon that is about to be fused with that of another, as I start to glean just what this experience might be. We are not quite finished talking when Tim's father, Brian, arrives. I need to be told: "This is Dad", because this is a man who, because of divorce, has been somewhat excluded from Tim's day-to-day picture - certainly when in hospital, anyway, or so I imagined. His dad is only too happy to contribute his story.

My meeting with Tim's mother is scheduled for that evening. Once again, I am ushered in to a familiarity that facilitates the rapport-building process. Ann has remarried, and has two little boys, Ryan and Dylan, who are excited to see me. Had I been interviewing siblings, they would have been very willing participants indeed. They are, however, ushered off to bed. I engage the record button and invite Ann to

tell me her experience, an invitation she may have subconsciously desired for twenty long years.

I do not know why I had not considered Tim's step father as a contributor, but it was only as I finished my post-interview cup of tea that Stuart volunteered: "I would really like to be part of your research." Late though it was, I explained the project and ethical constraints to him, and away he went, bringing a sense of completion - the final facet of that family's experience that the other three members had nearly, but not quite, portrayed.

To have executed four such interviews in one afternoon and evening was, on the one hand, intense, but on the other meant that I had indeed immersed myself in their experience; and this research project was off to a solid start. I reflected on the privilege that such a process accords the researcher by being entrusted with the intimate details - joys, pains, hopes and despairs - of not-always-strangers. Attendant to this is the charge to be conscientious in my dealing with their stories. It occurred to me that Ann had not only supplied *her* family's details, but she had described, as it were, a template of those who had lived through two decades moderated not only by CF, but also informed by hope-proffering discoveries and innovations, and transient goal-posts - a rapidly and radically shifting horizon into which subsequent participants could mentally be slotted. Displayed photos of Tim at two, four et cetera, could have been a representation of the other participants at that age. Now he had reached the age of twenty-one, but how had it been along the way? From my reading of the literature, I knew that a two-year-old's parents today are delivered prognostic predictions of a more positive kind. Would it change their experience, such as at diagnosis - minimise their trauma, lessen their shock? I had ideas, but what was I really going to find?

### **"I knew I was different straightaway"**

For Tim, telling his story seemed effortless, a stream of autobiographical detail that bubbled animatedly, punctuated with humour, over a foundational medical discourse. He relayed his life thus far, in which CF had been a constant presence - at times overt, and at others, hidden.

### **Future: cancelled**

After preliminary banter, he began his tale with hospitals and diagnosis. A notable absence was the telltale CF cough, which enabled him such free flowing recounting. That missing sound was replaced by another more intangible – a persistent ticking that metered his life, sometimes going slowly; at others speeding up, beginning when a 13-month-old sickly baby boy was diagnosed:

*I was sick as a baby. They didn't diagnose me until I was 13 months old, and the whole entire time Mum was taking me to heaps of different doctors, and they were just saying she was a neurotic mother and I just had colic. Meanwhile I was putting out green smelly, not smelly actually, it was putrid poo, because I wasn't digesting my food and I was crying all the time, and in the end she finally found a GP who said: "I think he's got CF"; and I was diagnosed finally. After that I was pretty fine. I didn't have any chest problems at all, and then I got pneumonia when I was seven, and that sort of knocked me around a bit. I recovered fairly quickly.*

From the start, Tim's body did not permit him the usual experiences of life. It acted in defiance not only of norms for contented babies, but also of the maternal comfort proffered by his mother in her attempt to bond with him. How endless the arduous hours and traipsing to "heaps of different doctors" only to have that most primal of relationships - mother and child - invested with a neurosis. The pronounced diagnosis of CF divested her of that tag, as roles reversed and Tim became the labelled one.

### **Moving goals: elusive age**

*When I was born Mum said that they said I wouldn't live past the age of 10 or whatever, then I got to 10 and then they said you probably won't make it until 15.*

The dragging time of that first onerous year was suddenly cut short, and replaced by a defined set of years with the potential to pass at a converse rapid speed. It was his mother who initially conveyed this to Tim, and thus was engendered a diametrical opposition within that relationship, as the very one who would want to endow her child with life was left to frame its finiteness with her words.



Tim considered that he was “a bit too young to comprehend”. However, when he was “about 15 or 16”, it was a doctor this time who told him:

*“Yes, you probably have only a couple of years,” and that hit home a bit. I was sort of depressed for a little while and then I thought, oh, well. I got over it like I usually do.*

As you do when your lifespan has just been redefined, the goalposts moved closer, and you are reminded that the game clock is ticking, counting down towards the end of play.

### **Knowing the difference**

Tim said: “I knew I was different straightaway”, and immediately went on to tell about his enjoyable sojourns in hospital, where he spent his 7<sup>th</sup>, 10<sup>th</sup>, 13<sup>th</sup>, 15<sup>th</sup>, 16<sup>th</sup> and 19<sup>th</sup> birthdays:

*When I was [in hospital] I would love it because all the nurses were so nice. I actually, there for a while, I would spend about two weeks in hospital, and when I came home I would be upset because I would miss everyone at the hospital, and it would take me about a week to readjust to being home again, and I used to love going into hospital. In later years of primary school, I used to go in every holidays just for what we called a tune-up, just to give me a dose of antibiotics, just so I wouldn't be sick during the school term. So I wouldn't miss any school and yes, I wasn't really that sick. I used to wreak havoc and I just loved it. I got to know all the staff very well. I was one of the favourites obviously because I am just so special [laughs]. I really enjoyed it and it wasn't until probably that I got to college that I started not liking going to hospital and I wanted to socialise, and I liked going to hospital and seeing everyone and stuff but it was interfering with my life. When I was younger it was just fun and I didn't like the needles and stuff but like, hey, no one does.*

Obviously this boy was quite at home in that institutionalised public space that was by no means unfamiliar. Neither were the staff and other patients to whom he related with the ease of friend or even family.

### **Respite years: covert body**

Besides his hospital holidays, his childhood years presented him with a window of relative normality in which he could enjoy pursuits such as athletics and be “really good”.

*I was really good at athletics in school. I used to always win the races at the school carnivals, and then we would go to the All Schools Championships, and I would win there, and I won the trophies at my athletics club, and right through primary school. I was really good.*

### **Friends and confidants**

*I have always been, a lot of CF's that I know, some people I have met, I can't fathom that they're best friends for five years and their best friends don't know they have CF. I don't even know how they can manage that. I would meet somebody, a complete stranger, and within a couple of hours they know that I have got CF. I don't care that people know. If they have a problem with it, stuff them, that's their problem. I'm really open about it and it doesn't phase me. That's why I do interviews like this. I'm not ashamed about it. Nothing to be ashamed of.*

In the background were his parents. He depicted his relationship with them as an open one:

*Mum and Dad are always really open with me. They've been really supportive and they don't keep anything from me, and so it has helped me a lot.*

It is with a note of fondness that he qualified his relationship with his mother:

*Oh, Mum and I just get in each other's way. It is just that me and Mum have a love-hate relationship - we love to hate each other.*

His parents did comprehend the doctors' predictions and Tim portrayed them as having to:

*Bully me to have my nebs because I hate them, because I had to spend 20 - 25 minutes doing my nebs and that was 20 - 25 minutes that I couldn't be playing or something like that.*

They would play board games to help pass the tedious time.

### **A turning tide: the body overt**

Nuisance, however, gave way to necessity as Tim started getting sicker:

*When I got to high school and I started getting a lot sicker and by grade eight or nine, I was losing races all the time and started to get too sick to do PE. In high school it went very quickly, and grade ten I had my worst year.*

As the body that had been his vehicle for satisfactory living was now unable to sustain his pace, time started to “go very quickly”. This decline was punctuated by an episode of haemoptysis, resulting in three weeks in hospital. What was his reaction to coughing up blood? He recalled:

*I remember thinking: “Oh, shit”. I don't even know if I actually thought that yes, I am sick. I remember being told that I was going to be lucky to be seeing the next couple of years, when I was about 16. He said, the rate I'm deteriorating I wouldn't be able to last another couple of years, but then luckily Pulmozyme came in and that basically saved my life long enough to get the lung transplant, Pulmozyme did.*

But this time and the rest of his high school years Tim relayed not in terms of fun, relationship or achievement, but rather documented it by the months of attendance missed in each year.

Likewise his university study was interrupted by the deferment of several years; “because I had my lung transplant, which is very exciting”, he declared at this point of the interview; almost like an announcement that the shorts have finished and the main feature is about to begin. After all, how many young men have such a tale to tell - a drama of such proportions in which they are the star?

Behind such bravado, however, I sensed that lung transplantation was neither an easy option nor natural progression, and represented perhaps, the lesser of two evils.

### **Life on hold**

A life in decline was now put on hold as the lad who loved to run, roam and relate was restricted to staying in the confined space of home, his horizon extending as far as the letterbox - a boundary moderated by his breathing capacity. Thus physically and socially confined, time dragged and became:

*Annoying because I had to wait. The wait was such a pain, because I had to basically put my life on hold, because being on the list you had to be ready to drop everything straight away to go to Melbourne, and that meant that I couldn't go away anywhere, do anything. I had to limit my activities to during the day because most of the calls were of a night time, so I couldn't go to the Cinema or anything like that ... it was just a real hassle.*

For someone with a confessed ambivalence to the transplant scenario, what prompted his decision?

*The doctor said that if you don't have the transplant you probably won't make your 21<sup>st</sup> ... To start with I wasn't even going to get the transplant, but when I was in hospital with my friend who died in the room next to me, I sort of decided, I had better do something or I would end up with him, and yes, I went on the list.*

No carefree days of youth, this was a difficult period, as is reflected only too patently in this poem that Tim penned in the midst of it:

### ***Why?***

I sit here alone.

Feel nothing but numbness.

I want to cry more,

But my tears are all dry.

It isn't true,  
He can't be gone.  
The emptiness I feel,  
Will never be filled.  
I see his smile that devilish grin.  
He's telling me he's okay, but I can see in his eyes.  
He's hurting deep.

His frail body now a corpse.  
That bastard disease did it.  
I hate it.  
I want to kill it.

I want him back,  
Just to say goodbye.  
I had no warning.  
He shouldn't have died.

I clasp his photo,  
Trying to find happiness in my soul.  
I know he's happy now.  
His suffering is over.

My selfishness wants him back.  
I need him; he's part of me.  
I can't go on,  
Take me instead, please.

(Dedicated to the late Sam Wilson. My mate forever)

### **False alarm: not time**

A decision for transplant made, he settled in to wait for lungs to become available, a time in which Tim counted:

*Twenty false alarms on the beeper. Every time it beeped I just looked and went, yeah, whatever. I was actually driving down Main Road the [first] time and it went off and I just started to panic. I'm not ready, I'm not ready, because it was only a couple of weeks after I had been put on the list, and they were saying you have to keep a bag packed and I hadn't packed the bag or anything and I thought, oh, no and then I went to a phone box and it was local calls only, I couldn't dial STD with it and so I had to go to another one and finally got through, and no, no, we don't want you, we haven't even thought about you.*

He vividly recalled the place where the first precipitate summons occurred. It was the juncture where he was propelled from transplant being later - an event to come - to the possibility of it being in the present - and back to an obscure future again in a matter of minutes, in which no packed bag preparation existed, and those who were masterminding his cataclysmic treatment had not given him a thought.

### **I'll be waiting**

From such height, he was deposited back into the realm of those who wait, aware of a declining connection with friends, the outside world and life itself. Time on the one hand dragged, yet on the other was reflected in each counted off day on the list which signified 'no lungs today'; a fact that had finally defeated his friend Sam a year before. How must it be to wait in a body that is doing its best to evict you?

Likewise, how trusting you would need to be of those in the transplant team who you first meet when they are assessing you, then diagnosing you sick enough for listing, and now are the arbiters of the subjective process of allocation. If ever there was a relationship in which power - of life and death - was invested with one party, at whose mercy crouches the other.

### **The call**

Tim was absorbed in *South Park*, his favourite television programme, when the phone rang:

*They said: "Hello," whoever it was that called me. I said: "OK, guess what?" I said. "You've got some lungs for me, don't you?" and she goes: "Well, maybe. I'm just*

*ringing to put you on standby. We've got to finalise some tests. You will get another call in an hour to tell you whether we are ready for you or not." I said: "OK," and I put down the phone and calmly walked out to the lounge room where Mum and my step-dad was, and I said: "I have just been put on stand-by for my lung transplant," and my Mum said: "OK" and my step-dad said: "What, what?" He was like starting to really panic and everything.*

And Tim went back to his room to see the end of the show. Now that the long awaited - 12 ½ months - event was actually occurring, was it in some way an anticlimax, or an unreal phase in which going from *South Park* to the phone summons was simply passing from one fictional world to another? Likewise was the Royal Flying Doctor plane that carried Tim and his dad into the darkness to land "over there" - Melbourne at 11pm. He recalled:

*I wasn't thinking. I was just numb. I got prepped and everything, I wasn't phased. I didn't have any feelings, because it was so surreal. I'd been waiting so long I just couldn't believe it had happened.*

### **Finally done**

Waking up in ICU, Tim described:

*I had a tube down my throat to breathe and the first thing I said when I woke up was, I need a neb, because I couldn't breathe because of the tube. They said no, he doesn't need a neb, it is just a psychological thing. When they took the tube out was pretty horrible because it felt like it ripped your throat out.*

His initial reaction to surgery was of necessity limited to one word, a note of triumph akin to finally scoring a soccer goal, perhaps:

*I got a pen and paper and started writing straight away and the first thing I wrote was "hooray" and Mum said she wished she'd kept the bit of paper, but she didn't. I wrote the hooray because it was finally done.*

This sentiment re his new lungs was tempered by not being able to move, and uncontrolled “shocking pain”, especially from the “big fat drains”. Being told to cough with four of these in his torso:

*Was the worst experience I had in my whole life, and all through it I tried to think, though, it is going to get better, it is going to get better.*

Such agony and determination to achieve a new phase of health was like a frail emerging from the chrysalis by the butterfly that has left behind an encumbered existence, and is propelled in its struggle by the knowledge that it will fly.

Tim contributed his poetic appraisal of this process:

### *A New Life*

The sun slowly sets,  
in the red western sky.  
Dark storm clouds are emanating.  
The cool wind turns icy,  
penetrating the soul.

As the light turns to dim,  
consciousness fades in and out.  
The reassuring voices of the world,  
slowly teatering [sic] off in the distance.

The clouds become darker,  
And rumbles are at the beckoning for all to hear.  
Then comes the rain.  
The saturating, penetrating rain.

Now falling upon total darkness,  
As the sun has vanished,  
And the moon is eclipsed by the black of night.



All consciousness has been rendered D.O.A.  
The last rites are gloomily being recited,  
As the spiritual beings mass in the gathering place.

The lighting strikes – ZAP!  
The thunder booms.  
Can there now be a glimmer of hope?

The lightening strikes brilliantly again,  
Piercing the darkness like a needle.  
The consciousness of the soul,  
Jolts in anticipation.

ZAP! ZAP! BOOM! BOOM!  
Nature flurries as her life giving elements go to work on the celestial skies.

Suddenly the darkness begins to disintegrate.  
A new moon is visible.  
The storm subsides and the state of the unconscious,  
Awakens from the depths.  
The sun replaces the moon,  
And hangs jubilantly in the blue of the atmosphere.  
She has brung [sic] with her, mother natures best gift.  
The gift of life.  
A brand new life.

#### **A new body**

Such a new state requires various adjustments.

*I had 74 staples ... I thought, oh, nice scar. I can't go topless anymore, big ugly scar,  
scare people.*

Tim's frivolous banter betrayed his subtle shift from a disease that was physically hidden - the scarring was on the inside - to the graphic, classic smiley face scar of the slice that grins from axilla to axilla.

There came, too, the psychological adjustment to the invasion of his body that this indelible mark represented:

*Actually nothing really happened until a week later and then I just broke down. It sort of took about a week for it to actually sink in, that hey, I've got new lungs and all of a sudden one day I just crashed, an emotional mess, and if Dad hadn't have been there I probably would have died I reckon. It was just awful, I would just cry at the drop of a hat.*

### **Familiar faces in familiar spaces**

Far from being apprehensive in the ICU milieu, this young man, who had been so habituated to such surroundings, dubbed it:

*A bit tedious after while, because I was fully conscious a lot and it was really hard to sleep in there.*

Being accustomed to hospital environs and the people therein, also meant that he did not feel isolated, besides his mother being present. On the contrary, he "fell in love with" the nurse initially prepping him - "she was really cute", tamed "Jane the social worker", befriended a girl who had a transplant four weeks later, kept a concerned eye on the wife of the 60-year-old in the next bed, and ingratiated himself with a Swedish doctor, whose apartment was a few doors up from the one in which he convalesced, and who allowed him to use her computer - despite the commands being in German.

### **Silent partner**

There was one female he did not get to know, however, but with whom he became intimately acquainted, and to whom he felt indebted - the woman "in her late 20's" who donated her lungs, and other organs as it turned out. Tim pondered:

*I think I am now ready to write a thankyou letter to the donor family.*

Sent anonymously via the donor co-ordinator, some families apparently elect not to receive such missives, while others are glad to hear. Tim planned to write:

*I am a 21-year-old male who received your daughter's lungs, and tell them how I am going and everything. It helps them to know what's happened to the organs.*

What relational threads does this instigate, as this grieving family choose to either believe that their loved one's death has enabled the life of another, or that in some perverse way, a part of her lives on inside him?

Interestingly, Tim then disclosed his post operative complications, which included straining fluid off "my" lungs, signifying a full appropriation of his replacement organs, and the mental discarding of the old.

Such discussion was obviously getting too intense for Tim, who needed to interject the sombre mood with some humour:

*I got told a couple of transplant jokes which I have to tell you: What's the worst thing about having a lung transplant? - Coughing up someone else's phlegm!*

### **Complication and compliance**

An expected complication was steroid-induced diabetes mellitus, which Tim explained:

*I've always thought that of all the diseases diabetes would be the worst one because you have to monitor what you eat and test your blood sugar all the time. At least with CF you only have to pop a few pills every now and again. I always never wanted diabetes and then when I got it, I was just so crabby.*

Not the comparison I would have made of those two diseases, but I have not lived with them, nor have I endured years of one, been through gruelling surgery, and hoped for relative disease-free liberty.

Tim, however, was negotiating his freedom, pharmaceutically anyway, and was taking control by virtue of his own personal risk/benefit assessment:

*I am taking my rejection medication because I know if I don't get that, it will kill me. There has to be something really, really major for me to do it. Like I know with these other things, they help me, but I'm not going to die if I don't.*

### **Extra time**

Tim now plays indoor soccer weekly and plans to register for the Transplant Olympics. Future plans are still moderated by his relationship with his friend Sam:

*Even if you keep living for his sake and I am now at the stage where I can't die now because I've got too many things to do. I have got a set of things now that I want to do and I have to do them, so - tough!*

### **A future perspective: from letterbox boundary to big city**

With the benefit of hindsight - and new lungs - Tim redefined the house that pre-surgery had been the extent of his world, and potentially his last view:

*It is not my space now. My little brothers are at me because I am their big brother and they just love me to death. I love them too but they can't understand that I need my space sometimes and yes, it gets a bit too much sometimes. I am sick of being at home.*

Was he sick of being at home, or was home where one was sick? No longer bound by his corporeal restrictions, his dependence on others, or a timeframe in which days are notated in a big countdown, Tim could resume previous plans and situate them in contexts that represent another time and another place.

*I am moving out next year though, because when I go back to Uni next year, I am going to move out and then hopefully third year I am going to do that at the other campus. I need a change of scenery and I will be moving to the mainland hopefully too, after I graduate, just for a little while.*

### **Not sick anymore really**

Confirmation that plans are well underway is obvious in Tim's comment cum declaration:

*I will probably get rental assistance because I am on the Disability Pension, but I don't know how much longer I can get a Disability Pension, because I'm not sick anymore really.*

### **A philosophy on life**

It would be usual to speculate whether people like Tim ever wonder: "Why me?" Without the need for a question, he volunteered his philosophy of life:

*I am of the belief that people get things for a reason, and I got this for a reason, because whoever decides people's fate, thought: "Well he's strong enough to cope with this problem," and so they gave it to me and then they felt: "Yes, he can have diabetes on top of that if he likes and give him osteoporosis too, because he's really strong." Sometimes I feel like going: "Stuff you." I was afflicted with shortness [laughs].*

### **New beginnings**

And so it was that a young man shared his life, and near death, with me, the researcher. I like to think it is also with me, friend, because of his being relationally attuned that is how he makes people feel. I paused at this point, grateful that on a certain day, transplant co-ordinators did think about him.

## Brian

No man is an Island, entire of itself; every man is a piece of the Continent, a part of the main.  
- John Donne *Devotions xvii*

Having never met Tim's father, I was looking forward to talking with this man with whom I felt acquainted because of Tim's account. This was the one with whom Tim went to live at nine years old, an arrangement not sustained, however, when Brian's new partner was unable to cope with the intrusive disease that attended the cute little boy. Tim returned to live with Ann and Stuart, and Brian's relational dilemma was solved. That would have been a major quandary for him, because, as I found from his talking about Tim's transplant, a relational focus was inherent in whatever he would do.

Because of his more flexible circumstances, Brian was the parent elected to fly with Tim. This was an experience that sat outside normal, confirmed by its inhabiting a dimension outside normal time, seeming rather to have taken "just a split second". He spent the next 2 ½ months in a somewhat translated state he described as a "very strange time", which I perceived him to be assessing according to the quality of personal interaction it accorded him.

Thus his observation of ICU was that it was "very clinical", with its "cubicles and things like that". But his summation goes further than the space:

*Normally, they only come in [to ICU] for one or two days and when the patients start reviving, they send them out; but Tim stayed down a long time, and the nurses got to know me as well, and most of them don't know how to emotionally get involved. A couple of them did in the end, started to really care for Tim, and I think that's why most of them seem to work there - it's very clinical. Cubicles and things like that. People are just parcels coming through.*

Having considered both the demeanour of the nurses, and also the partitioned structure, Brian concluded that neither were conducive to the kind of communication

he anticipated. In the midst of that technicality, his antennae were tuned for emotional currents, initially investing the nurses with perception that saw the patients as “just parcels coming through”.

He seemed to subconsciously set the making of contact with people his goal, proffering and looking for hospitality:

*In the end there was quite a few nice ones, and of course you get to meet people. That's what I thought was really good. You are in there, people come in and it's just automatic recognition of why we are there; and I ended up being invited back to a Christmas meal by Melbourne people.*

I was glad to hear about this invitation because this was one man I sensed would not cope without a family fireside on such a day. This began a succession of introductions and connections, which became the fabric of his very personal account:

*We actually got to know a female doctor over there. She was from Switzerland, and when we stayed at the apartment she was only a few doors up. Had us up there for a couple of meals, got to know her boyfriend.*

His interaction was by no means one-way, but resulted in his being an ambassador for the state from which he felt a long way. Ownership of this invested him with identity - the Tasmanian in a contrastingly big city. He added:

*They ended up coming over. They booked to see Cradle Mountain and so I had them at my place and gave them a Tassie treat: smoked salmon, breads and cheeses. I got an email a couple of weeks ago. I have to write back to them actually.*

By no means seeking passing incidental interludes or holiday encounters, this was a man who was fostering enduring friendship:

*Made some lifetime friends over there, that's for sure.*

Leaving the confined hospital setting, Brian went for walks across several suburbs. At times his city wanderings saw him disorientated, and not knowing the intricacies of which tram to catch:

*A young girl piped up and said: "Do you want a tram?" I said: "yes". I hopped on the tram with her and she was talk, talk, talk, talk, talk, and she was saying what it was like over in Tassie. She wants to do environmental courses and said Tassie was the best place. What's Lonnie like and what's Tasmania like? What are you doing over here, and all that sort of thing. She was very, very friendly. Some people were very nice and some were very ignorant.*

Once again, his ambassadorial qualities were appreciated, and he had found someone else who had been friendly - and "nice", because all were not. Those he deemed "ignorant", I wondered, did that mean they did not notice him?

*They walk straight past you. Here [at home] when Tim used to go in hospital sometimes, I would walk outside and people would be looking at you, because they could see what's going on with you.*

### **Don't mind me**

It would seem that in the big city, he felt like one of those ICU parcels - but a body actually unnoticed, or clandestine. He reflected:

*Over there, it didn't matter how low I was feeling, they would just walk straight past you. They didn't even recognise you or notice you there. You are alone, alone. Yes.*

He was mentally comparing an island town with a large city, taking the small population characteristics of familiarity and friendliness, and superimposing these upon people who did not anticipate seeing a known face, nor the same one twice. Because he could not reconcile the two, it was a lonely experience for him.

I found myself pondering just what he expected - to run into friends in the vast metropolis? Thus was I dumbfounded when he told the tale of the Russian taxi driver.



## **One in a million**

*There was a Russian taxi driver, found out I was a builder, gave me a card. He wants to come over here to Tassie and build eventually, once his family gets out of Russia. He said: "Any time you come back to Melbourne give me a call". Gave me his mobile number and everything. We are talking about 3½ million people, and Sal went over. She went over and she hopped in this taxi and told her destination and he worked it out and he said: "Oh, that's not the boy who just had the lung transplant is it?" And it was the same guy.*

Brian needed and sought personal contact and support. These dynamics were vital for his coping with being the carer for Tim for those two and a half months; and his stay in Melbourne was difficult until he was able to put relational ballast in his world.

In amongst all this relational recounting, I wondered where Tim fitted. How was he relating to him? Brian explained:

*Hours of the days, like Tim was able to sleep or was out to it for a long time; but for me, no, many, many nights. I stayed all the time in the doctors' quarters. Just a room, but I was always close.*

Obviously an unfamiliar hospital setting is not conducive to lengthy bedside sitting, when your loved one is not responding. In subsequent weeks, however, Tim and his dad enjoyed the opportunity to be "open with each other and talk a lot;" and being able to go for uncharacteristically long walks and intensive retail therapy. For differing reasons, both felt let out, Brian particularly as he had felt:

*Being over there was just like being in a prison. You were allowed a certain amount of freedom but I got bowled up a few times by the security. I had a pass to go round the hospital, a card you have to have to go in and out of the hospital, but it wouldn't let me into the IC area, so they still had to let me in and out; and when Tim was going back to his room, one of the nurses, she wanted it, and I said: "No, it's mine. I need it to go to bed". But she wanted it right or wrong, but I said: "No, you're not getting it".*

This father who had come to be the support for his son now felt imprisoned in a building that because of its size only enhanced his institutionalised feeling. Comparing it in both size and colour with his local, familiar hospital, Brian recounted:

*The entrance floor has got a newsagent, a chemist, a post office, a hair salon, a book shop. It wasn't like that before but now the university is in the hospital. And they have a huge cafeteria there.*

### **Paying the price**

The experience was obviously not an easy one for a sensitive man feeling displaced. He described:

*No, I couldn't eat properly and then I had very bad digestive problems when I came back, and what they call a mucous ball, a fur ball, floating around in my intestines causing havoc. I paid the price for it as well.*

The strain accumulated over two and a half months did not dissipate upon return home:

*Tremendous amount of stress and everything. I started to have a couple of massages before I left Melbourne because they had an in-house masseur and I went to see him, to try and relax me a bit.*

Emotional build up and pressure manifested in physical symptoms as his body endeavoured to alleviate his mind and emotions:

*But it wasn't until I came back here I was able to do something more dramatic and drastic about it, and a lot of them said the spark had gone. You could say I was depressed, and I was like that for months, and didn't know whether I was here or there or what. I didn't change. I wasn't a bad person. Nothing mattered much. Go to work, yes, do this, yes.*

Ann had told me that she considered Brian not to have coped well when Tim was first diagnosed with CF, and the original burden of care had fallen on her shoulders. She likewise knew that he would find it difficult caring for Tim after his transplant.

Just as she told of wanting to breathe for Tim when he was initially in ICU postoperatively, was Brian's body in some way wanting to absorb the stress of an emotional kind, and do some of the work for Tim? Once again, a desire for some vicarious corporeal substitution, a making amends for the latent trauma one body originally invested in the other. Or was it a force of a different kind?

### **All you need is love**

Brian reflected:

*If you asked me could I go through it again, I wouldn't say no. It's a hard thing. In my mind I wouldn't want to, but I would do it because love drives you, nothing else. A lot of people said to me over the years, friend's wives, said: "How do you cope?" because we've had to look after Tim for years. But they say: "How do you do it?" I say: "I don't know, it is just love." Simple as that, you don't question it. It is just there and that is the only thing that got us through all the pain over there.*

So ended a different account of the experience of living with CF, one that was not littered with medical details and chronological history. Rather it was Brian's reflections on being "over there", as he often referred to it, as opposed to "here", where he is at home and in control - and no doubt awaiting more visitors and emails.

## Ann

When I get to the bottom  
I go back to the top of the slide  
Where I stop and I turn  
And I go for a ride  
Till I get to the bottom  
And I see you again.  
Helter skelter ...

-John Lennon/Paul McCartney, *Helter Skelter*

### **“It’s a roller coaster ride”**

It was while listening to Ann’s story that I gained a fresh understanding of just how unique perception is, that one person’s reporting of an experience, relationship or setting can be either complimentary or in stark contrast to that presented by another player in the same scene.

### **The ride starts here**

Ann began her story at diagnosis, and I wondered whether this would be a pattern throughout this research project. On reflection, I could see why that is the place to begin because that was the starting point. While symptoms already existed, CF had not formally entered this woman’s - this family’s - life until official identification. This was the one definite event before life became “a bit of a roller coaster ride from then,” an erratic, unpredictable journey, the cessation of which occurs with the only other definite event - when the death of one releases the others.

This woman, who first heard the name CF when it was used in the same sentence as her baby son, needed no second bidding to speak into the tape. She had waited a very long time for this:

*The disease wasn’t even picked up with him until he was 12 months old. He had shown all the classic symptoms and I was taking him to a normal GP and basically was being told: “You’re a neurotic mother. Take your child home. There is nothing wrong with him”. I got very frustrated as a new mum does, and at his 12 month check took him to a different doctor and sort of “something wrong here” straight away, and he was sent to hospital and had a test done, and when they first told me - I didn’t*

*know what cystic fibrosis was or anything like that - and they basically said that he was going to spend most of his childhood in hospital. He'd be lucky to see the age of 15, et cetera.*

Not only did a disease entity enter her domain, but also some new, unidentified members of her relational aspect, "they", who did the initial telling, the painting of the original picture, and the placing of the age limit. Through repeated contact over the years, these unfamiliar faces in strange surroundings translated into: "The hospital is my second home and I walk down there and I know every second person", even concurring with Tim's considering these people "as family and I do too."

But what was her initial reaction to the scenario?

*So of course, I went and walked out of the hospital in a state of shock. I mean, I remember the initial reaction was that I had this little 12-month-old baby in the hospital there, and I put him into his crib, and I just had to walk out of the hospital. I couldn't even hold him. This wall came down in front of me, and that was dreadful.*

Rather than being offered the cessation of the weariness and frustration of that first year with a sickly child, Ann was confronted with its continuation in a course that appeared incongruently endless and yet finite. Her leaving Tim and walking out represented both a relational and a physical separation from him, punctuated by a seemingly tangible edifice that she had to scale.

Anne recalled "a time period" in which she thought: "I don't really believe you", which:

*Only lasted about 24 hours and once I got over that I thought, right, okay, let's get our act together. This is what we've got to do. I thought, well, he's going to have to spend all this time in hospital. Gee, can I cope? I might not have him at 15.*

Describing herself as “a positive person who always looks on the bright side”, Ann’s conviction was punctuated with metaphor and cliché, a cache into which she obviously dove over the years to alleviate whatever was confronting her. She added:

*I’ve always been a very positive person and I believe I’ll cross that bridge when I come to it. I’ve always said to people I could have been blessed with a perfectly healthy child who walked out in front of a bus and was killed. So I’ve always taken it day by day, and I’ve always stressed that it’s the quality of life, not the quantity of life.*

But his demise was not threatened by a third party random collision with an inopportune bus. It was rather the calculated stakes that had resulted from the relationship of Ann and Brian, with an ensuing impact of another kind:

*I think because of the pressures of having a sick child, I think that probably contributed to my marriage break-up. I think there was probably a little bit of blame, not at the time I don’t think, but in hindsight I think that probably deep down, we were blaming each other for the fact that we’d had a child with CF.*

I found the notion of blame to be a fascinating one, considering that both parties have to be carriers of the CF gene. But maybe the apportioning of blame goes deeper than genetic contribution, to their having actually formed a relationship in the first place. These dynamics ultimately resulted in the severing of the union that had permitted the recalcitrant genes to connect, and to produce the outcome that had cast a negative shadow over its future.

### **Just do it**

Describing Brian as not coping “particularly well”, Ann portrayed herself shouldering the care - doing the “nebulisers, had to do physio, and all of those sort of things”, while the CF daily ritual “was very difficult”. There was a sense in which Ann did not know any different:

*Because Tim was my first child, I didn’t know what it was like to have a healthy child. Basically, this was my life, this was my child. He has to have enzymes with his food,*

*he has to have special dietary needs, he has to go to the hospital, he has to go to the doctors, he has to do this. But I didn't know any different. I think if I'd had a healthy child first, I probably would have found it a lot harder to cope with than what I did because Tim was my first born. You just did it.*

It was on the one hand, a burden, but on the other, it represented a structure of familiarity that sustained her when other aspects of this life with CF were well out of focus:

*I've got a very ordered life. I think that also keeps me sane because I have structure and I have routine and so forth. So if something happens, that's what keeps me going - my routines and my structures.*

### **No favours**

This ordering of the world by the structured functioning of the body represented a coping and a creation of normality. Such an accent flowed into Ann's relating to, and treatment of, Tim:

*My attitude with Tim was, yes you've got this sickness but you have to learn to deal with this. We're going to bring you up as a normal child and we're not going to treat you any differently or give you any extras because you're sick.*

Inherent in this sentiment is the notion that the sublimation of the sick role, and the pretence that it is a standard body, will lead to a normal child. And what of the corollary? For all her striving to treat Tim as a so-called ordinary child, Ann could not normalise his body. It was later in the interview that she reconsidered this concept of normal, arriving at a different conclusion:

*I think any child or any person with a life-threatening illness are special, and they are different, I don't care what anyone says, not different in a bad way, but different in as much as they look at life in a different way. They're more understanding and I think they are a lot more mature than a lot of other kids their age. They have to deal with a lot more.*

## Enlisted

Such striving on Ann's part would explain her reaction to Tim's original reluctance to proceed with lung transplant. She described an initial anger because he would not take this opportunity to prolong his life, thwarting the very aim that had driven her relating to him and her care of his body. That anger gave way to understanding that he was scared. She witnessed this fear being transposed with a fear of dying, precipitated by Sam's death, enhancing Tim's recounting of this with:

*It was probably the day after Sam died that Tim said to me: "I'm going on the list, Mum." So I think he was scared to have the transplant, but I think he was more scared of dying, and I think Sam passing away brought it home to him. He was in the room next door. He'd been sitting up eating pizza with Sam the night before. It was a dreadful thing for him to have to go through. Being so close, going away on camps together and that sort of thing. I'm very proud of Tim.*

Decision made, this woman who copes by structured routine, conceived a game plan in which all the players in her world were assigned specific moves. These plans were frustrated by her considering:

*One of the biggest problems, and something I would really like changed, is that they have this thing about Tasmanians only having one parent. Now when Tim was sent over they had accommodation for one parent. They paid for a plane fare for one parent. Everything was for one parent. So really unless you're willing to pay for it, either Mum or Dad has to stay behind while your child is over there having one of these transplants done, which I think is absolutely ridiculous considering that other states will pay for both.*

Logistics deemed that Tim's dad accompanied him on the flight across Bass Strait:

*I drove his dad and he over to the Royal Flying Doctor's. Luckily we live very close. It was ten o'clock, I think, it was late-ish. That was hard, seeing him take off with his dad. I sat in the car waiting for the plane to take off.*



On an icy, fog-tipped night, this mother made the driving dash that for years she had known she would do, and for months had rehearsed just how. She deposited her son into a tiny plane that carried him away from her, pregnant-like in its belly, up into the darkness from which those odds that do a lot of saying decreed he may not return.

But Ann had a strong conviction:

*When he went on the transplant list I didn't even contemplate that he might die before he got his transplant. I knew that he was going to get a transplant. I had such faith in the doctors over in Melbourne, blind faith, but I knew that they were going to pull him through; and I also have a lot of faith in Tim himself, that I know that he is going to look after himself the best way possible.*

And so a mother hopes.

### **I see you**

Ann spoke at length about the transplant ordeal, and their enactment of the panacea that had always existed as a remote last option. She described her reaction to seeing her son in ICU postoperatively:

*You know the first thing I thought? My God, he's pink. His nails and everything else was pink whereas for years they'd been blue. I was oblivious to everything else, absolutely oblivious to it.*

This was an observation of his body. However:

*The most emotional moment was about three days after his operation when he still couldn't talk, obviously because he was very sore, so he was writing everything down, and he just wrote: "Hurray!" That brought me to tears and I think that was the epitome of the operation.*

I considered the stark contrast with a hospital setting some two decades before, when a new mother walked away, removing herself bodily from her sick child. Now twenty

years later in an ICU, she described: "I felt while I was there he was safe." She expressed a desire to "gladly change places" - which she did, in a sense:

*When he slept he had a tendency to stop breathing. I remember sitting in the hospital rooms watching him breathe and it got to the stage where I couldn't do it because that was sending me insane. I was actually breathing for him. That's always been my biggest fear that I'll see him stop breathing.*

### **Breath of life**

But she could not help his breathing. She wanted to stand in - her body for his, her body to try and bring correction, her body doing what it should have done in the first place - engendering long normal life. But another woman did - was able to give that life, was able to take his place, occupy his body. But they're "just organs" when "the soul was well and truly gone", then the gift is given:

*A lot of the emphysema patients only get one lung, so of course in the hospital you will have two people with one lung each. They got into the stage of classing each other as brother and sister, or this is my brother and he's got the other half of my lung. Or there was the man who got the heart from Tim's donor. His wife kept referring to Tim as being related to John in some way now, because he had the lungs and her husband had the heart. I took offence at that because of the way we looked at the organs, that they were just purely organs. They could have belonged to anybody.*

And the "just organs" are responsible for executing every breath her son will now take. The breath of life had originally been given in life, but now in death. Either way, it came about selflessly from a body which pre-elected to give life.

"I hope she didn't have children", said Ann.

*I feel very sorry for her in that regard, but as far as looking at Tim and thinking you've got someone else's lungs in your body, that thought has never, ever crossed my mind. Never, ever.*

But for the moment, such conversation had been tense enough for Ann. Time to lift

the mood; and I saw her employ the light relief tactic that Tim was also wont to do:

*The only thing that we have stirred him about is that because of the drugs after his transplant, it is quite a common occurrence, they go silly spending money. I think that it's just that one, they've got a new lease on life and two, the drugs get rid of some of the inhibitions. They basically told me: "Don't let him have a credit card. We've seen people run up \$2,000 on a credit card after a transplant." Anyway he did. He was a shop-a-holic. And I often say to him, it's the feminine side of you coming out. That's about the only thing we joke about.*

Ann and I laughed, not only at the thought of Tim laden with shopping bags, but also with great relief that he was enabled to do so. But Ann needed to add a footnote comment:

*But as far as thinking it's something alien in his body, I've never, ever thought that. To my knowledge I don't think he has either.*

### **A double-edged death**

As Ann spoke, my mind made a silent comparison. When Tim was born, there already existed a little girl whose family were not delivered devastating news, but rather would have held assumptions for her of not only a long, healthy life, but also to outlive them. Cancellation of this prescription by untimely death, set in motion what had been hypothetical for one family, while in another home, an anticipated scenario was now, finally, to be enacted. The former would have struggled with notions of altruism to see them through their grief, while another mother somewhere breathed a sigh of relief:

*If he hadn't had it I wouldn't have him now because I really truly believe he would not have lived through this winter. So this is all bonus now. This is all extra. Even if we lose him in six months time, we've been given extra time with him; and to see him now in comparison to twelve months ago - he's got his life back and I'm grateful for that, and if he can go out and do some of the things that he wants to do now, and we lose him further on down the track, so be it, as long as he's been able to enjoy the time he's got because, let's face it, none of us know.*

## Happy returns

It was not easy for Ann to return home at the end of the first week, to leave Tim and entrust him to his dad's care until she returned six weeks later. She described her almost atmospheric re-entry into space that she no longer perceived the same:

*It was an adjustment coming back home more so than being over there, because all of a sudden I came back here, and everything was the same. I came back here in a state of shock that night. What am I doing? Yes I'm back home. Next day I got up and had to take kids to school. It was just sort of bang, like that, back into the old routine again.*

This time, Ann did not slip into place, patterns and protocols as she had previously done, nor did she derive comfort from them. Normal was just too far removed from the scenario from which she had just come. But another metamorphosis had also occurred: "You never come back the same person."

Ann talked on - and on and on - a torrent of story, a delving deep, an exhuming of the phenomenon not unlike an archaeological dig, as she brushed sections of it clear with her words. She concluded:

*I guess it's changed me in some ways having a child with CF, but in a lot of ways it's probably made me a stronger person as well. In a way it's probably made me the person I am today.*

## Stuart

Time, that is intolerant  
Of the brave and innocent,  
And indifferent in a week  
To a beautiful physique ...

-W.H.Auden, *In memory of W.B. Yeats*

It is an intriguing experience to meet someone that one has already heard discussed and assessed. I was aware of having this insider information, but approached each interview with a sense of freshness, aware that it would be an as yet unconsidered perspective that each participant brings. So it was that I rolled the tape for Tim's stepfather Stuart, having heard much about him from Tim and his mother.

It surprised me when he began the story with a contrasting description of Tim as having a lot to put up with:

*Growing up in a broken home and being sick and an only child. And then after Ann and his father split up, he stayed with his father, and his father got remarried, and that was all right for a while, but then there was some problems there and he came to live with us when he was twelve or thirteen.*

This was a succinct summation compared with the rambling household details conveyed by the other three informants in this family. But I was now hearing from a relative newcomer.

I silently recalled Tim's describing their relationship as "we don't get on." Stuart acknowledged the difficult dynamics of a step-parent interaction, perceiving he and Tim to be "on a really good footing together and a real good relationship now." He proceeded to paint a picture of how hard being ill and the daily treatment routine had been on Tim. He spoke with the sensitivity and insight of one whom I sensed had reflected in depth on the CF experience, being moved to tears several times in the course of the interview. "Little kids shouldn't have to suffer that," he declared.

## **Mortal reminders**

Stuart recalled an incident when Tim was about 13 years old:

*He was put in a ward with another CF kid. They just thought they'd put them in a ward together. They were the same age and had both got CF and Tim actually picked up a couple of bugs from him that he previously never had those particular strains or whatever; and that baulked him because that young boy passed away another year or so after that. Tim was fairly blasé but cavalier with his attitude toward looking after himself. But at the end of the day, he did the right thing - this other boy didn't. A kid that age shouldn't have to have that sort of mortal reminder.*

He considered further:

*Yeah, when you become middle age you should only just start to be comprehending those sort of lessons.*

## **Waterloo and watershed**

*He was lucky enough to go away on the Teenage Adventure Camp to Queensland. We were quite happy for him to go, took him along to the airport. He was fairly quiet and nervous, and a lot of the other kids who had been before or they'd been together the night before, because they were from down south and north-west, so they'd sort of started to make friendships, even before they'd got to the plane. He was the new boy. He went away on that trip. He came back a different kid, and those were all similar scenarios, life-threatening illnesses, not necessarily CF, not necessarily cancer, all sorts of things. And they came back and they were like kids coming back from war with a special understanding of their mortality and making the most of life.*

Their precocious knowledge and understanding of mortality was in some way stealing more of their life with the robbing of their naivety. Stuart tried to compare this experience with one of his own, the nearest he could get being scout trips on which he made friends, but conceded that those held nowhere near the weight of the friendships he witnessed with these mortally ill young people.

### **Milestone or millstone**

Tim's 15<sup>th</sup> birthday was obviously a noteworthy landmark because Stuart was the third family member to mention it; reiterating what had become a dominant theme in his discourse - that "kids shouldn't have to be aware of those sorts of things." He recalled Tim's offhand comment that morning: "Oh I didn't think we'd get to this one", not unlike "it might rain today." However, Stuart conceded: "Die an old man he probably won't." He then enunciated a fear to which Ann had also alluded - that of Tim ceasing to breathe, something "you never really sort of talk about," but which, I imagine, may not have required transformation into words:

*He used to lay in bed at night and you'd hear the oxygen machine going all night. It didn't sound much different to a refrigerator but it was there. It was going. Sobering. Never really talked about it much but sometimes you'd get up and not hear any movement in there, cause he's a bit of a night owl. He'd sit up late anyway. But when you knew he wasn't real well you'd hear him come out of the bedroom and ooh. You never really sort of talk about it but that feeling's there that, is he laying in bed dead? And you don't know, you can't keep coming in seeing if he's not. It's there in the background all the time, especially at times when his cycle was down.*

So the house became a space diffused with blatant mortality - of one of its inhabitants, anyway. Stuart was part of this scenario, not relationally by flesh and blood - and genetic - deposit, but by his contribution of an emotional commitment.

### **Over there**

For Stuart, Tim's transplant meant that Ann was away in Melbourne for six weeks separation, during which time he cared for Ryan and Dylan. Separation of husband and wife, mother and sons became arduous, so he arranged to take his children on a surprise visit. Seeing is believing, and there was a sense in which sighting Tim relieved uncertainty. While they knew it had happened and kept in phone contact, it had been left to their imaginations to construct Tim's new bodily form. He exceeded their limited expectations:

*Just to be able to see him get around and do that and it was only like six weeks after the op. The transformation was unbelievable. Such a quick transition. I suppose,*

*medically, once the body is getting oxygen properly, it's sort of like a plant that hasn't been watered properly. Once it's watered properly it will take off, won't it? That smile, you know, I don't think I'll ever forget that. When we arrived there, he was just sort of standing up there: "Look at me! Look at me! Look what I've come through!"*

### **Making meaning**

It was near the end of the interview that Stuart sought a purpose for all that this family had endured, proffering his explanatory philosophy thus:

*You have these things, they come to you as a challenge. It's experience that life gives you, and what you can take out of it afterwards is what you really learn. You can say, what do you learn from having a life-threatening illness like that? There's lessons to be learned from life, different things you do. And if you don't look at what something teaches you, well what's the point of going through it?*

Does having a purpose make the experience more bearable? Does endowing it with a reason help its victims to make sense of it?

### **Family ties**

For Stuart, life is not lived with retrospective buts and what ifs. Rather he expresses a readiness to:

*Look to the future and we've got quite a good family unit and quite proud of it. The photos in the foyer there, they were done near the end of June. That was this year. We're quite proud of that. That's our family.*

I had seen those photographs on the way in. Not that a visitor could have missed them, actually. They covered the entire entrance hall wall, depicting little boys doing cute things in snaps that will doubtless embarrass them in years to come. My only hope is that the number of those so depicted does not decrease from current ones, calculated by Stuart thus:

*The five of us, not the four of us and a stepson. It's the five of us and that's our family.*



## Bob

---

I still haven't found what I'm looking for.

- Bono, U2.

Yet again I am following a set of directions on how to find a young man who I anticipate is waiting to divulge his unique story of this lifeworld that is appearing more each interview, and coming into sharper focus. I knock on this door, aware of the significance of that act. This house belongs to 18-year-old Bob, who has just moved in with some mates, having worked hard to purchase it for himself. He shows me around, including the established garden and barbecue for "having friends around". More than bricks and mortar - and lawns to mow - it represents plans and possibilities for a future. After much digging amongst copious cartons in the kitchen, he produces two mugs. Holding steaming coffees, we sit in the sun as the tape-recorder stores his reminiscences. He talks not only about the years that have accrued to get him this far, but also dares to dream and paint for me a projection for those ahead. Now that he has reached 18 - got this far - he can permit himself to indulge in such a luxury.

The following evening, I interview Bob's parents, Nigel and Clare, whose stories complement Bob's and broaden my view of this family's life thus far. I am introduced to his two younger sisters, Brie and Lucy, who have had their own vivid experience with illness unrelated to CF.

Behind where I sit, the wall is festooned with family photographs. Their response to my commenting upon them is to indicate various favourites and classifying them in relation to before or after one or other of the children's more dramatic illness episodes.

### **"I was the one in four"**

"I make a point of enjoying everything I do", Bob told me, and this philosophy applied equally to the interview I had with him. This was a young man whose CF care had spanned three islands. Now living in Tasmania, it was to King Island that his

parents took home their firstborn 18 years ago, only to fly back to Melbourne with him a few weeks later “when I got sick”.

“My parents, Mum and Dad, almost lost me”, he confided. “How careless” I wanted to say, but it was not a humorous moment. It referred to the initiation of an imminent awareness of death for this family, first for the parents and then for their son, because as Bob shared: “They never kept anything from me.” Regarding his having CF: “I think I always knew it.”

*It was embarrassing when you were a little kid, but because I was always in hospital and I wanted to know what that was for, because I was in hospital a lot when I was young.*

Childhood for him was punctuated by regular hospitalisations “a couple of times a year for tune-ups.” Such a regular servicing is usually associated with pursuits automotive rather than a small boy. It seemed inappropriate to reduce him to a wonky vehicle, but such is the nature of life-threatening disease, existence in the realms of time, space and relationship is ultimately dependent upon housing in a well-oiled machine.

This involved flying to Melbourne because there was a “better hospital”. So for the first 12 years of Bob’s life, CF meant a lot of flying. “We did a lot of travelling,” he recalled.

His having CF meant a plunging from an isolated rural setting into a contrastingly big, cosmopolitan, tertiary, hospital. Was this traumatic for Bob? It would seem that he reconciled this difference, actually deciding that:

*I used to really like the Children's Hospital in Melbourne. There are things I really remember. Because it was Melbourne, both my grandmothers were around that time.*

### **Gone fishing**

By virtue of the place having become familiar and the continuity of family relationship - “I had four grandparents that lived over there” - this young frequent

flyer recalled vivid, positive memories. He adapted a city cum clinical experience to one more befitting this boy from the bush:

*There was a big park and a zoo right near the hospital. I used to go to the zoo quite a bit, and the park. We used to go yabby fishing down there in the ponds. Just put a line in and bring them back to the kitchen, cook them up in the kitchen. I actually got - there's a little cut, see that? That's from dropping a bowl on the floor of the Royal Children's Hospital kitchen. Good for a laugh, that memory.*

Bob continued his hospital recollections with a notable emphasis on the people who inhabited that world:

*They were great staff. It was great. Used to have a good time. The physio was good there. Had a pretty good time with the physio. They made it fun.*

While those with CF may talk about their holiday hospital tune-ups as fun, there always hovered the latent life and death potential of the disease. Fun and, indeed, arduous treatment, are no amnesiacs for experiences such as the one Bob then told me:

*I guess one of the only things I remember is - must have been 8, 10, about that - one of my friends, I didn't know him that well, dying in the bed just opposite me one night, cause in those days it was six to a room, something like that. But one guy, he was very sick, I think he was about 21, 19, 20 or 21, something like that, I think. One night he died in his bed.*

It was intriguing that although Bob did not “know” this young man very well, he nominated him “my friend”, a relational term for those, perhaps, who have shared living quarters, shared a disease label, and a prognosis. What, I wondered, went through Bob’s mind, sharing that room because your body has the same disease as another body in there, which has just expelled its owner? He died “in his bed”, a normal place to be at night, just like Bob was doing? Was he witnessing a prophetic act?

It was not an area into which he was ready to delve further. 'No fishing' this time. "It's the only time I've seen someone dying, or been next to them," he calculated, as if others had had more opportunity to be so situated, and for him a similar possibility exists. I silently recalled Tim's account of his friend Sam dying in the next room. Now the experience had come closer - it was in the next bed.

### **School days**

Primary school did not rate a mention by Bob. It seemed to have been subsumed in his hospital adventures. A big change came at 13 years old, however, when Bob went to a boarding school in Tasmania, which still meant much flying, albeit over different scenery this time. Despite returning home twelve times a year, the fact that he had "no relatives in Tassie" meant that friends were important. But the first two years of boarding school were:

*Pretty shocking. That's probably the worst two years of my life, those two at boarding school, because I didn't get a whole lot of friends.*

Bob was not a newcomer to an institutional setting. Hospital stays in Melbourne had been "a good time", but now there had been a change. He attributed this to several factors, explaining:

*Just before I left King Island, I was really strong in my Christian faith then and I got a lot of flack from them about it, from the other guys in the boarding house. So I didn't have a whole lot of friends there.*

So overwhelming was the boarding school experience that:

*It got to the stage at the end of the second year, at the end of grade eight, that I was going to go home to the island and give up that school, but Mum and Dad didn't want that so they moved over here.*

What role did CF have in this *annus horribilis*? It was another dynamic that he perceived only served to isolate him further:

*I just had to get up earlier than most people and go over to Matron's and have my physio there. It took about half an hour or more each day, and the rest of the day I just - had a bit of trouble because I had to eat lots of high calorie foods. I got special treatment from the boarding house kitchen. So for breakfast I used to have hash browns and stuff no one else would get. I'd go to the kitchen and get my hash browns and take them out there and eat them. At lunch I'd have a bowl of ice cream that no one else had. Bit of special treatment the boarders can't have. Milkshakes to keep my calories up. They didn't like that much. That could have been part of the problem, the social aspect there, the fact that I got the special treatment and they didn't get it.*

No matter how much he tried to fit in and make friends, by virtue of compliance with the CF regime, he was different. While his body did not appear markedly different, it was not the homogenised body. It had unusual requirements. Any attempts to keep CF marginalised were thwarted by the overt nature of the treatment - the early rising, ritual physiotherapy with the matron, and the extra goodies at mealtimes. For Bob it was not a case of dare to be different. Did he have any choice in this structured, supervised environment? It would have been hard to be torn between fostering relationship with friends and being an ally to his body and caring for it.

Hash browns and ice cream - not so tasty when no one else is permitted to enjoy them, when the people you are trying to befriend view them with composite desire and disdain. What did these students know of CF? Did they grasp the subtle link between special foods and life-saving treatment - a difficult correlation in anyone's mind?

Was there an announcement or did Bob tell one person and the boarding school grapevine did the rest? What impression did they have? Were they worried he might die in his bed?

*They all knew that I had CF, that was why I was having it, but they just didn't like the fact that they couldn't get it. It didn't matter. I got to the stage where I didn't care what any of those guys thought about me. I didn't do a lot of stuff with my friends. I was very independent.*

I imagine he had to be, as CF situated him in a somewhat isolated position. It was a

relief to hear that school life improved and “ in year nine, ten, eleven and twelve I had a whole lot more friends”, as students matured and they became used to him. They were no longer suspicious of this disease whose leap may not be imminent. Plus he was good at sport. His final two years at the school saw him part of a “strong group of friends” he dubbed the “the high achievers”, some of whom invited him to stay at their homes, and continue still to be in touch.

### **“I’ve got CF.”**

The nature and allocation of personal space during his boarding school era afforded Bob no opportunity to be a discrete CF sufferer. Not to divulge this status was not an option in this milieu of enforced compliance. It engendered, however, the following resolve:

*It’s not an issue for me at all to tell people that I’ve got CF. I won’t make a point of saying, but if something comes up, for a reason I can’t do something or why I don’t smoke or anything like that, then I’ll say it. Coughing and they’ll say: “ Have you got asthma or something?” I’ll say: “I’ve got CF.”*

“How do you explain it?”, I asked Bob.

*It’s a chronic illness that I was born with and will have for life. It affects my lungs and my digestion. The digestion means my pancreas doesn’t work, so I have to take enzymes. That’s basically it, and also my lungs produce excess mucous, so I have to have antibiotics. That’s basically what I tell them.*

### **A year off**

Bob continued the interview with the declaration: “I’d had enough of school for a time. Took a year off, best thing I’ve ever done” - an extravagance for someone who has a limited supply and is counting? Or a confident decision by one who has passed original lifespan projections, has cast a retrospective glance and reconceptualized time, and can afford to look around a bit - ‘smell the roses?’

This proved to be no bludge year, however, but the opportunity to try “six or seven jobs.” This motivated young man was not biding his time but obviously counting on a

future. Bob attempted very physical employment, having not only the strength but also the vision to do it. He did park work, ten hour days with a team searching for oil in the bush, and tree planting, which he was not so good at, only planting “five hundred a day” when, in order to “get decent money, you need to plant a thousand.”

Having also done pizza delivery, he secured casual work with a supermarket chain, which would fit in well with the aquaculture degree he planned to study the next year. I saw that the year off had been a stepping-stone in the fulfilment of plans he dared to have. He envisioned:

*A job. A good, well paid job. Well paid is important. In that career, aquaculture which I've chosen, in that career, that's what I want.*

Bob also pursued physical endeavours in spite of his CF status. This focused young man not only excelled at orienteering, but professed: “I love canoe polo, kayaking and outdoor stuff.” He encapsulated this drive in his anecdote:

*One girlfriend used to live across the river... It was basically opposite each other. It's half an hour drive or a ten-minute paddle. So I often used to paddle across there.*

### **Family ties**

Thus was instigated a conversation on relationships, one that in earlier years Bob may not have imagined:

*I guess the only thing I really think about with myself is having a family, because I want to have a family. But Mum's told me from what she's heard a large proportion of males with CF can't have kids without IVF. But also with CF genes, obviously not only am I a carrier, but I'm a full-blown sufferer. So I'll have to be careful with my wife that she was not even a carrier, and I'm pretty careful having our own kids anyway. I reckon it would be one of the worst things, having a CF child. So I'd probably have a look at adopting or something like that. It would depend on her views on that. I think about that a bit, like what it would be like to have a child of your own.*

Now that time past has been lived, time present considered, and time future is an extending horizon, Bob has an established sense of embodiment because of the understanding that his corporality is not going to go away as quickly as he once thought. Thus this body would like to put out a replica of itself plus one other body. But tempered with this thought is a desire not to perpetuate a familiar scene wherein a future time, in a future place, an as yet unknown child could similarly contemplate his genetic inheritance tainted with regret.

### **A risky business**

Asked Bob:

*How do you become a carrier? You can't become a carrier if none of your parents are carriers, can you? I guess you can if there is a recessive gene. So you can get it passed down from two parents who don't have any signs of it. It can get passed to the child. So it seems to have come out in the open in both Mum and Dad. I was the one in four.*

I listened as a young man pondered his genetic burden. As a researcher, I always feel particularly privileged when people candidly disclose their lives in the name of data gathering. This stark moment being privy to Bob laying his hereditary hand on the table and contemplating his moderated game strategy, was one of the more telling moments I had in this research endeavour.

Usually conversations of this kind will see young men contemplating an attractive countenance and the like. For Bob, any starry-eyed dreaming of his intended's personality or demeanour is tempered by the uncertainty of her chromosomal heritage, and any heady romantic tryst grounded in the realm of "risky business."

Likewise at this age, youth are considering their body in terms of stature and physique, possibly mindful of the muscles underlying it, but not the essential content of every cell therein. It is here that CF can lurk until, as in Bob's case: "It came out into the open," a scenario he does not want to see repeated; a legacy he does not choose to bequeath:



*I guess then you've got the chance that if you see someone, and if my wife was a carrier, then the chances are more than one in four. So it's a pretty risky business when you talk about it. I've had a great life but I wouldn't want to give my child CF.*

### **An uninterrupted view**

Bob acknowledged the patronage of a higher power:

*I mean that's why, I think it's just the total reason why I've stayed so healthy, and I consider myself to be successful so far and stuff. It's all due to God. He's blessed me so much - and He'll continue to.*

I sensed that this fortification of faith permitted Bob an extra dimension of confidence in being able not just to glimpse an unknown future, but to enjoy the luxury of gazing into it. I was left believing that where it will present him with a challenge akin to a half hour drive, he will search out the point at which he only needs to spend ten minutes of hard paddling, because he does not have a minute to waste:

*It's not like I'm not thinking about the future because I don't know if I'll get there, because I trust I'll get there. I'll get there. I'll make it. Long way to go yet.*

## Nigel and Clare

Not once or twice in our rough-island story,  
The path of duty was the way to glory.

-Alfred, Lord Tennyson

**“... all at sea .”**

Nigel and Clare elected to talk with me together, a dynamic which was assumed on their part, because that is the way CF had been dealt with in their family. They began by regaling me with testimonials of others with CF with whom they were acquainted, either personally or via the efficient grapevine of anecdotal information that serves as a plumbline against which to measure one's own situation.

Nigel picked up their story with the predictable opener of diagnosis, presenting it from a somewhat irregular stance, which he nominated “interesting” because as it happened, they had both been studying genetics. So these parents were not unlike those who have done the pre-reading for an assignment or swotted for the biggest test they could ever imagine. Nigel proceeded to describe their initially being “really fascinated by it in the early stages and wanting to know what there was to know”, and their current position of feeling as though they had “lost touch with the research”. Nigel sighed: “I suppose you just get tired, tangled up in the overall living the life with the person with the CF.” Now they had assumed a starkly contrasting passive stance of: “I guess when the time comes that gene therapy is available, we'll be told.” What had happened in the time between first fascination and the plain weariness he now exhibited? What had living the life with the person with CF entailed for this family, who, as Clare expressed, felt “all at sea”?

### Great expectations

I sensed that there had been more to their initial response to diagnosis, and Clare picked up the narration of the tale of baby Bob, who did not pass a normal meconium, a detail that:

*Being our first baby, I hadn't really thought to expect that with great anticipation or anything. They just brought the baby to you, and they mostly changed the nappies*

*and did that stuff in the first 24 hours or 36 hours or so.*

Bob would seem to have been born in a childbirth setting in which hospital staff, by virtue of executing most of the care, assumed a quasi ownership of the child. Thus this mother “never really unwrapped him”, remaining “blissfully unaware that there was anything to be concerned about.”

Remaining unperturbed that “he was not really feeding”, it was on the second day, while her husband had taken a break from the hospital, that Clare was told that there “was a problem, you know, and I was absolutely devastated.” She vividly recalled seeing her distressed baby, who up until now had been a blanket-encircled face, now become a body she really gazed upon for the first time, unwrapped and displayed:

*On one of those sort of warm tables where they can work on a baby with no clothes on, not getting cold, heart monitor stuck to him and all this; and his huge little tummy. It was pretty distressing. They took him off in a newborn ambulance.*

The final statement conveyed that this was a journey in which Clare was not included, as they still seemed to exert ownership over this tiny boy. She was left behind to try and contact Nigel, who was obliviously enjoying a meal at a relative’s house. Surgery ensued.

#### **“What’s CF?”**

Believing their baby to now be cured of his bowel obstruction, it was Clare’s cousin - a paediatric nurse - who asked: “Have they told you about CF?” Their response was: “What’s CF?” Words they had never heard before entered their vocabulary and were planted in their minds as they uttered them in question format, the way in which it would be repeatedly addressed to them over subsequent years.

The diagnosis of bowel obstruction, which a day before had felt overwhelming, was now on a different scale of terrible all together. It belonged on the range of curable, although initial information into such matters was not readily forthcoming. Medical staff maintained priority not only of the body, but also over what was occurring therein, being cautious over how and when these parents would be privy also.

The surgeon's reaction to their asking about CF was: "Who told you that?" In retrospect, had they not done so, they realised that CF would not have been mentioned for several more days.

### **Just wondering**

As his bowel had to be rested for two weeks, Clare now saw her baby with:

*Tubes of red stuff and tubes of white stuff and tubes of yellow stuff all going into his veins. Poor little tiny babies, they have to find a little vein.*

Only gross graphic images so far for this new mother to store. Still he was contained - in the special care crib, in the ambulance, in the midst of tubing. They had questions, and not unreasonably "started making noises and wanting to know more."

In response to this, a team consisting of a liaison nurse from the thoracic medicine unit, a physiotherapist, a gastro-enterologist and a social worker was assembled. The cavalry had arrived. No longer in the dark, Nigel and Clare were surrounded by a team. No longer silence. There were people around them with whom to dialogue. Even then, however, they felt as though they had to extract any information:

*We wanted to know all the details, and there would be things where we would ask the question and they would hedge as if to say: "We really don't like to tell everybody all those details to start with." Because we were both biology trained, we just wanted the absolute details ... it seemed like getting blood out of a stone.*

Nigel recalled a survey in which he had participated that included a question regarding being told about their child's illness. He seemed perplexed at the results:

*Most people felt they were told too much, and here we were thinking we weren't told enough. So we were actually not necessarily the average person that they're trying to plan their procedure and the handling of people around. Obviously us wanting to know lots and lots and lots wasn't perhaps the norm, and so the reticence that they felt was perhaps because they were usually dealing with people that might have not coped well with lots of information.*

He expressed: "Our minds were going fulltime for this baby, wanting to know everything about him and why he wasn't well," as though knowing more - knowing all, in fact - would somehow ease the burden, alleviate the shock, make him better, perhaps. But facts in the mind do not nullify emotions of the heart, and here was one area in which the well-versed team was not effective. Clare painted a scene that was far removed from a supportive session, one that was striking in its aloneness and anonymous, non-therapeutic setting:

*I can remember sitting in a corridor sort of crying, and being pretty devastated because they made it seem like pretty much a short life sentence. I guess they made sure that we realised how lots of them didn't live. It was regarded as a fatal childhood illness. That's the way they described it, and when we tried to get some sort of idea of what life expectancy we could hope for, they eventually came up with a figure of, well maybe 18, maybe, you know. So that stuck in our minds so much as he got to be 18 and there he was really healthy. We went through the whole gamut and just thinking how terrible it was and maybe it would have been better if he died.*

Thus was the anticipated joy of the birth of their firstborn child stolen and replaced with a devastating saga enacted in a hospital where, because they were away from home, they were "just there full time". Said Nigel: "We really had time on our hands", not something you would want to expend an excess of in such a setting, when now your child's supply of time had just been rationed.

### **No place like home**

Most parents of acutely ill hospitalised children usually get to take their children home, and that is the end of the episode. Not so those of the child with chronic illness - it is just the beginning. Nigel and Clare flew home to King Island and attempted to resume the farming life that had always been "a dream", and attempted to assimilate their new son, and his disease, into it.

Clare had been away for seven weeks, two antenatally and five after Bob was born. She described her returning home:

*I'd been away seven weeks and it was just like - I didn't even feel like I belonged at*

*home any more, when you've been away for so long.*

During this time Nigel made two trips to Melbourne while Clare was "living", as opposed to staying, in parent's quarters. After such a length of time, it felt like her primary place of residence.

They were only home for four weeks when Bob had to be taken back to Melbourne to "close his little ileostomy thing". Yet again the effects of the disease detracted from the new life they were attempting to pursue, something that would continually occur until the vision was ultimately eroded.

Clare would have been relieved to be rid of the temporary ileostomy because caring for it "was by far the most traumatic thing." It must have been bad because the rest of his treatment sounded torturous - for them all:

*We were giving him basically raw enzyme powder mixed up into a slurry, and just used to use a syringe thing without the needle, and squirt it in. You used to have to cover his mouth with Vaseline so that if some dribbled down - even if you wiped it off really quickly, it would be enough to really irritate the skin - and you used to have to smother your nipples in Vaseline so you didn't get awfully burned from what was still in his mouth after he'd had it. Some of it used to come out in this bag, used to have this special double adhesive stuff ... but no matter how carefully you cut it to fit the stoma, inevitably a little leakage would get out and then you'd get all these awful ulcerated places on his skin where the enzymes would burn him, or sometimes the bag would leak. It was by far the worst part of caring for him because we were already giving him some antibiotics as a preventative, oral things.*

Their relationship with Bob altered in the daily wrestling to keep his body in subjugation:

*You had to become very hardened to the fact that screaming is good for his lungs. I'd have to put up with the screaming and you'd be thumping away. Then sit him up after a minute or so, then press the cough button so he'd learn to cough up anything that would come up into his throat. Of course a baby can't understand all this. It's just*

*highly unpleasant, so they're coughing between screams and it really is quite - yeah, with a small baby having to do physio is pretty traumatic.*

Such practice goes against the normal goals of placating your child:

*The entire normal baby world is devoted to consoling a crying baby and so here you are making your baby cry; and the worst thing is you had to do it before a feed when they were really crabby and hungry, otherwise they'd sick up their feed, tipping them upside down. So you had this distraught, starving, screaming baby.*

Clare bemoaned the fact that:

*You could never really just go up and listen and hug your kids, and cuddle them and play with them. You always had to do something to them.*

### **Handle with care**

The subtle threat against their normal relationship with Bob was not compensated for by family, amongst whom "nobody wanted to touch Bob - maybe one brave person." Clare conceded that because of his looking sickly and thin, this apparent fragility meant that: "People were scared he'd break and so for those years you felt a bit rejected because people were frightened to hold him."

### **Tubing revisited**

Just when I was beginning to think that these people's lives must have eventually evened out, they reiterated the closing of the ileostomy. Being warned of all theoretical risks including that of contracting bronchiolitis, they relaxed despite a slight elevation in Bob's temperature, as he had passed the appropriate bowel motions, a signal to "take a break" and enjoy a Melbourne market. Clare told of returning to find Bob's condition had deteriorated and he was intubated; and proceeded to blame herself. But maybe that is one way of dealing with anger which cannot be projected onto those upon whom you are dependent for future care:

*You just feel like a terrible mother because it happened when you weren't there, and you'd been hovering there, just about sleeping there, and you allow yourself a little*

*break and look, you pay for it now.*

### **A word of encouragement**

Bob had also demonstrated an allergy to cow's milk, his resultant blistered face adding to the myriad of symptoms with which he and his caring parents were plagued. Clare expressed: "We had a dreadful couple of years at that time," with the isolated setting of the island rural lifestyle presenting more difficulties. It was when Bob was starting to get "a little chesty" that two year-old Brie was badly burned. As a result, this family was tagged for consultation by a visiting Tasmanian paediatrician who, it would appear, "overlooked the fact that I was really struggling to cope with this beautiful little girl that all of a sudden had burns all over and a little boy with CF." Instead, Clare described this doctor berating her for carrying Bob's enzymes in a former theophylline container. That was obviously not her only indiscretion - Bob should have been having more physiotherapy, and she "wasn't looking after this child properly." This advice distressed Clare who anticipated a relationship resonant with support and optimism as proffered by the CF clinic, where "everybody is so encouraging and tells you what a great job you're doing."

This family anticipated assistance such as that extended by doctors in Melbourne:

*We always had good support from [them]. I used to ring them up if I had something I wasn't sure about so that they could give me an over the phone diagnosis. Also they used to send me home with cartons of stuff.*

### **City commuters**

But grass was not permitted to grow under this family's feet. The end of that fortnight following the paediatrician's visit saw Clare with her three children all in hospital in Melbourne, receiving a tune-up for Bob, skin-graft for Brie and allergy testing for baby Lucy. This was not long after Clare's own recent recovery from pleurisy and a queried embolus. Hence her conclusion: "It was just a shocking couple of years, really, really shocking" for this family in which CF was not always centre stage.

### **A good education**

Infant school on the Island necessitated Bob going on a daily journey involving a car



ride and a long bus trip, a process more akin to the cosmopolitan mode of life they wanted to leave behind. Nigel and Clare decided upon a home schooling programme. While this was a “huge, all consuming thing” for Clare, she was simultaneously “passionate about it.” It would seem to have been an era of their lives when they could actually appropriate both rural and parental aspirations, in a window of their experience that Clare nominated “really good years;” a statement this listener was pleased to finally hear.

I suspect it would have been difficult to eventually wave off 13-year-old Bob to boarding school on yet another island, and this time without his parents:

*It was hard not to be in charge of it any more, so you're sort of forever asking him if he'd done this and if he'd done that.*

Valuing a “good education [as] really very important” is the kind of statement made by a mother for whom the passing of time, the progress of treatment and the growth of her son has invested him with a potential future beyond the 18 years he was first offered when he was diagnosed. Education becomes not just a fill-in between hospitalisations but something to be deemed “good” and “important.”

*I think that perhaps, maybe you don't get it with all CF patients, if they're much sicker, then perhaps they do develop a little bit of a “Oh what's the point?” They miss too much school and get behind and start under-achieving. I'm sure that happens to some, but Bob has always been, I think, aware that his life mightn't be that long but he's going to make it count. He's always been very full on, energetic, into everything enthusiastically.*

Initially, these parents were the purveyors of information regarding CF:

*I guess we told everybody what to expect and about the tablets. Schools sometimes are very wary about self-medication. He was old enough at home to come and get the tablets that he needed, but at school he had to go and get them from the teacher.*

Bob's school then took the initiative, as Clare explained:

*Everybody that had him had to learn a bit about it. A couple of teachers went away to seminars that they used to run at the Children's Hospital. The Matron went away to one of those seminars. The school sent her over to attend one of those so she knew what to expect, and she could talk to anyone she wanted to talk to. We felt really thrilled that the school was prepared to.*

Nigel considered:

*She really used those skills, didn't she? She was just like another mother.*

Hence Matron's appreciation and rigorous delivery of daily physiotherapy, and the supplying of appropriate food supplements.

### **Sunset clause**

Their time on the island was coming to an end. Firstly came the awareness that Bob was not faring so well at school. This was exacerbated by incidents such as his having possibly unwarranted appendix surgery of which they were informed after he was in theatre. But it was 11 o'clock at night, so Clare flew over the next morning. Said Nigel:

*Interesting to know what would have happened if he'd been on the Island at that stage. I mean, he would have been flown to Melbourne then, rather than go to Tassie, and perhaps it would have been a different scenario.*

I was reminded of another mother awake at 11pm one night because her son - a plane ride away on another island - was having surgery.

So the decision was made to move to Tasmania, and the dream of having a farm was discarded in favour of another - to be parents. The two, it seemed, could not coexist at this time in their lives.

Clare spoke for them both:

*I think it's been harder for Nigel to leave the farm than I could have ever realised, at*

*the time. I think it's been a real, yeah, a real blow to him to lose something that he put so much dreaming and thought into. I think it's easy, because so much of my life had become - except for the first three years or so before we had the children when we were both equally involved in it - after that I was so busy with children things, and all that time away, that I wasn't as involved with the farm, not emotionally as much.*

Bob's statement that "Mum and Dad moved over" had not quite conveyed the full extent of this change, wherein his family negotiated a new place, new people and a different lifestyle. Hence Clare's apt comment for those who have island hopped yet again: "We all just lost our support bases", reiterating her sense that: "We were all at sea." On further reflection, however, she considered:

*I suppose we've grown up in isolation a bit. Bob really never grew ever really knowing any other CF people at all, and so coming over here, we didn't really look for that.*

On the other hand:

*If we'd lived in Victoria, I'm sure I would have got much more involved in the Association, which in the Victorian case became a very big concern, bought their own building and did all sorts of stuff, and right into raising money for grants for things, and supporting research, and doing all sorts of stuff ... has great big fat newsletters and research reports.*

### **Taking leave**

As is often the case with research interviews, the exploration of another time and another place renders both those participating and the one vicariously imbibing, detachment from time present; which by this stage of my evening with Nigel and Clare had seen both clock hands and tape spools execute innumerable revolutions. The thought of pressing bookwork for which this self-employed man was responsible delivered Nigel back to the currency of now, and he took his leave with the comment:

*She was doing most of it any way. She's the only one who can remember. I can't remember all of this stuff. I mean, it's familiar territory, of course, but mums*

*remember all the gory details.*

On the contrary, his contribution had been valuable and his insights legitimate, and for this I expressed my gratitude.

### **Letting go**

While Bob's going to boarding school was a physical separation from his parents, they were still the guardians of his care, and as involved in it as fully as such separation would allow. Now that the family had moved to be with him in Tasmania, a severance of a differing kind was instigated, one culminating in the now 18 year-old attending CF clinics alone:

*He makes his own decisions. I think he's got a good basic understanding of what might happen and could happen in terms of his own health.*

How has this process been for Bob's parents? While they would depict daily physiotherapy thus:

*There was quite a few years there that it was really a burdensome thing to have to do twice or even three times a day,*

I imagine it is not always so easy to stop intervening on behalf of this body with arduous, yet familiar, routines. To farewell these in some ways changes the relationship with the son who now needs to be a separate individual:

*It's just hard to let go of those ties when you have been the full carer of the child, and you know every little detail - bowel motions and everything - because it's been important, and you have to let go. He does everything now, and it's so much part of his life that he just doesn't think anything of it.*

### **Always a possibility**

For now, Bob's mother considered him to be doing well. Having talked with him, I silently concurred with her. She considered his future, his having a family of his own, and "how his health will be" because "you never know when something -", she

pondered. She was only too aware that after repeated pneumonia such people “just run out of lungs”.

But she had heard the stories:

*The people who 'd had the heart-lung transplant, some of them were incredibly successful. They're just like new people, like living without CF after perhaps twenty years. All they had to take was the anti-rejection therapy or whatever, which was nothing compared to what they used to have to do. Wonderful stories like that so you sort of think that's there for a last resort, you know, that is there. I feel that's a good thing to know that that's a possibility.*

The fact that that scenario would demand a precipitous flight across a stretch of water in a small plane, possibly at night, as dwellers of a small island evacuate to one larger, is a process in which these people seem well-versed indeed.

## Hannah

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I am the family face;  
Flesh perishes, I live on,  
Projecting trait and trace,  
Through times to times anon,  
And leaping from place to place  
Over oblivion.

-Thomas Hardy, *Heredity*

I knock on the door of my next participants on a sunny Saturday morning, aware that 13 “and a half” year-old Hannah will still be at her gym session, a deliberate arrangement by her father Ross, so that he can be free to talk with me without the presence of the central player in his drama. This has not been an easy appointment to make, interrupted by life in the form of a series of hospitalisations for Hannah, plus her attending several CF clinics without her guardian, and the unsettling business of their having to relocate to a new rental property when the one they were in was one that they liked. But nothing seems easy for this family, bereft of the common CF tableau of two concerned parents striving together as complimentary dual supports. This house is permeated with an aura of frugality and signs of struggle not just limited to the material domain.

## Ross

If you have any tears, prepare to shed them now.

-William Shakespeare, *Julius Caesar*

## Lone ranger

“Where do you start?”, Ross asked rhetorically as, given the opportunity to talk about his life experience, he was mentally confronting a very large package, and was seeking out that point where unwrapping could begin. I should not have been surprised that he settled on diagnosis as the ‘pull tab here’ moment; but in this man’s case, it was intertwined with another cataclysmic occurrence:

*I wasn't living with Hannah when she was diagnosed. She was living with her mother [Louise]. Her mother died just before she turned three, and she came to live with me. But she wasn't diagnosed until she was two, or eighteen months to two years old.*

Because "there wasn't a standard test at birth back then", Hannah:

*Was in hospital with bowel blockages and chest infections, and really sick for the first couple of years of her life, until they worked it out. So when she came to me, we were still sort of, I mean she had only been on enzymes for a short time, and we had to sort of - she had a lot of severe tummy troubles.*

I could commiserate with his summation that: "I was taking on a big thing." At the same time, I pondered the vicarious participant in this interview - the mother who was party to the unrelenting care of Hannah for those first eighteen months, only to be relieved from that pressure by one of greater weight - her inscription with a disease label. In what way was Louise's reaction precipitated by not coping with everyday life? Ross considered:

*Well I already had Chris and Donna, who were then probably seven and eight. So when we separated I had the other kids right from the start.*

Ross had painted a background for me. It was a necessary introduction from which he could proceed to unfold his subsequent experience.

### **Not at home**

Ross switched to the topic of Hannah's care:

*I've had some real hiccoughs with the hospital over the years ... Professional families, if they go into hospital and say, this is what's happening, they listen to them a bloody sight more than me.*

These people were part of the cohort of 'others' against whom he perceived he and Hannah to be arraigned, circumstantial inadequacy rendering him mute in a system in which he could demonstrate neither eloquence nor status. He was *au fait* with neither

appropriate language nor interaction norms, and bereft of a partner, had no backup who could compensate.

Thus for Ross, hospital represents one of the main spaces in which antagonistic interchanges occur. Even gaining access into the place he considers a challenge:

*We've had times when she's been really sick, and we've had to go through the outpatients thing for five or six hours, just to get up to the children's ward. When she went in last time, I got a phone call at work. It was Hannah and she could hardly breathe. She was having an asthma attack. So I said: "Ring a taxi and get straight down to the hospital." So luckily she was able to ring a taxi and get down there. I raced in to the hospital and they had her in a cubicle in casualty there but they hadn't given her anything to help her with her breathing. So I went upstairs and found the Registrar and told her what was going on. So she raced straight down and got her a nebuliser organised, and stuff. But it makes you wonder if I hadn't gone in, would they have left her there like it? You know?*

Once inside, interactions ensued that left him feeling "inferior", and a "pathetic excuse of a father." His suggestion to one doctor of moving with Hannah to a warmer climate interstate was met with:

*Oh it might be all right for you. You can sit on the beach, but it wouldn't help Hannah's health at all. And he said it really condescendingly, like I'm just a bludger who would sit on the bloody beach. I mean it would be better for me to sit there than sit here freezing I suppose.*

The beachcombing assumption was made without the knowledge of Ross's being on the waiting list to "have me hernias fixed", and not appreciating that this, coupled with Hannah's being sick, meant that he was unable to work at that time. It was at this point that Ross added his positive hepatitis C status to the retinue of medical problems this family manifested. I wondered whether Ross's seeking faraway places to move to was not only for Hannah's health, but also offered the possibility of new places and fresh faces.



## A long line of events

He reiterated further interaction in which he was required to advocate on Hannah's behalf in a setting in which the "social worker was waiting for me at the door":

*They're having trouble getting the veins. All the veins are stuffed in her lower arms and whatever. So they did the Infusaport, but before that they tried the long-line. They get it in eleven centimetres and it would get stuck and pull it out, and then they stuck it in the other arm eleven centimetres, got stuck, and pulled it out. Blood was spurting everywhere, of course, and Hannah just sits there. I wasn't there for this. I heard about it. She told me about it. I mean I was at work while they were doing this. They just decided to try the long-line. She wanted a port. The next day they took her up to intensive care and did it there, or in theatre somewhere. They got the long-line into her, and they generally last six weeks. Well Hannah's lasted four days and got infected. Anyway, these are the sort of things that just worry a parent, I suppose.*

This anecdote was framed with a palpable despondency - that the long-line was unsuccessful, and that Hannah's request for an Infusaport, a means of easier venous access, went unheeded. The graphic scene of the spurting blood et cetera was relayed as through Hannah's eyes. He had not been a firsthand witness, and that was his biggest frustration, that he could not be breadwinner and advocate. In the case of the latter, had he been present, would he have been rendered silent anyway by virtue of the status that he felt had been conferred upon him?

Imagine his subsequent dissatisfaction when, with a sense of *déjà vu*, a doctor from an intrastate hospital phoned him. Hannah had been holidaying with "some of her mother's family who of course, all had the flu", and Hannah ended up sick and hospitalised. She required intravenous antibiotics, a treatment that was held up by her overused veins resisting cannulation.

Ross was quick to explain the recent trauma of the long-line saga, only to be met with the doctor replying: "I'll make that decision on whether we try a long-line or not." Once again, it was not only distance that alienated this father from advocacy. It was the subtle separation of knowledge, will and perhaps the inability of either party to recognise the previous experience of the other. Whatever it was, Ross once again felt

the loser in the interchange. Realising you cannot 'fight city hall', Ross settled into the impotent resignation of: "Who am I to complain?"

### **Outside interference**

It was yet another doctor from a different city who diagnosed Hannah's arthritis, prescribing prednisolone, an unpopular decision with her local treating team, who "don't like it anyway." In fact, "the hospital hated it," Ross told me, investing blame not in individuals, but conferring it upon the whole institution represented by the building he could now view from his house. It was during one of Hannah's incarcerations there that "they wanted to put her on a plane and send her to Melbourne to see this arthritis specialist", a suggestion he "knocked back." This resulted in the local trial of various anti-inflammatory medications. It was then that he told me:

*She nearly died one day on the way from town to home. She's down as asthmatic as well. One of the warnings on the packet is not to give it to asthmatics. I showed them this and they said: "Well it doesn't happen with everyone." But the kid nearly did die, one Saturday morning. We were walking back from town. Didn't have an asthma puffer. I was half way between home and doctor's. I couldn't get her to either one. She was just standing there having a bloody asthma attack. So I just tried to calm her down. Luckily she come right.*

It certainly was, because although the fact of death had featured variously in this man's life, the potentially premature one of his daughter is one for which he is not ready; and which he has devoted his energies to warding off. He lives with a constant sense of threat, just hoping "she doesn't pick up a nasty infection," because "that would probably wipe her out". That expression in this instance implies removal so that there is no visible trace, rendering not only a void where once the thing existed, but also in the focus of the one left to contemplate the demise.

It was not that Ross "knocked back" the Melbourne consultation because he did not trust their potential care. It was not their input he shunned, but the plane ride to get her there, because she was quite ill at the time. So they had been isolated from those he considered trustworthy allies, describing one of these Melbourne paediatricians as:

*Excellent. He actually helped us get through this arthritis thing as well, you know, made them take notice down here.*

### **A means of escape**

Such subliminal truths have manifested in Ross's over indulging in "the grog":

*I have a bit of a drinking problem and some nights, well I only have four cans and I'm half full. After a hard day's work and if I haven't had tea and I have four beers, I'll be, as far as Hannah's concerned, bloody drunk. So she'll say: "Don't drink tonight Dad." So if I walk in and I've had a drink, she's likely to walk out. And that's what she did about six weeks ago. She said: "I told you not to come home and drink." She's like me mother sometimes. Who's wearing the pants around here? I go to work. I just want to come home and have a couple of beers.*

Hannah's response was that of a child who had assumed a measure of relational authority, displayed in the mothering of her father. It was also that of a child who was not only well acquainted with institutional support structures, but also capable and adept at negotiating their procedures. Ross recalled receiving a phone call from the social worker, who by that action had moved from her metaphorical standing at the ward door, into the family space that was his home.

### **Home away from home**

The phone call was to advise Ross that Hannah had removed herself because she did not feel "comfortable" and was being housed in alternate accommodation. He explained:

*But when she first went to this Family Services thing the first time, it was a real treat to have Austar and the Internet and all this stuff. She went for a few days and she thought that was all right. And they would put her in some bloody mansion they've got. The first time she went, we didn't have the Internet. So I talked to the social workers, the ones involved, and they said they think she's treating it just like a posh hotel because there's no family that she can go to, and she's stuck with us all the time. After about the second time she did it, they were about a couple of months apart, they thought that and they made me go to the counsellor to modify the drinking and*

*whatever ... Got to go back and see the counsellor and I haven't done anything about it yet because it means taking time off work.*

Seeing the counsellor would not only mean negotiating practical difficulties such as time off work and connecting bus services. It would also engender discussion of personal issues that would have implications requiring attention. Hannah's moving out demonstrated that she did not view their home as a refuge. It also signalled that she was not happy with their relationship. Any fracturing of that would hold possibly greater implications for Ross, because if the one who he stands with against all others were to defect, it would appear that he could be in a very isolated state indeed.

### **Starting again**

So while medical environs seemed hostile, home for Ross was another dynamic again, albeit his refuge of a temporary kind. Having rented the one house for eight years, their recent move was obviously not at their initiation. Rather it precipitated not only a dislocation from familiar territory, but also the reconceptualizing of daily time and routines, now that Ross had to catch "two buses to get to work and two buses to get home." Likewise it required the establishing of new relationships in a place that did not yet feel like home. There was no next-door neighbour with a lawnmower you can borrow in exchange for letting them putting put their car in your garage, because you own neither car nor mower yourself - just an overgrown lawn and a garden that threatens to get out of control without the proper care. The attendant weariness at this point in the conversation made me think that Ross did not need anything else in his life that demanded vigilance.

### **Otherwise**

I started to formulate a picture of Ross being against all those who were 'other' in his world, not the least being Chris and Donna, Ross's older children, for whom living with CF is a drama in which I sensed they have struggled to play:

*I've had my son leave and come back. He's been back for six months. He blames Hannah and all this drama. And the 18-year-old daughter, she left at 16 and my son thinks that all this drama played a big part in her leaving as well. He's very short-*

*tempered and he thinks that Hannah gets the most attention and the most time, and all that sort of stuff, with her illnesses.*

I considered this to be a legitimate claim from a young man who was berated for coughing “all over Hannah” and not seeking medical attention when he was sick with influenza, because of the risk to her. Sibling relationships would not have been fostered in an atmosphere of comparison:

*Hannah's a really big help actually. It's amazing because the other guys were never helpful. Hannah is different from Chris and Donna. She's been so consistent with help over the last six months. It's just amazing actually; she's just so grown up.*

Thus his apparent rejection of his older children is the action of a man who is using all his energy to maintain the *status quo*, and for whom the prospect of coping with anything more seems beyond his ability. Such ‘one-too-many’ include possible infection for Hannah, negotiating any further along the rocky adolescent road he described Chris and Donna travelling, and the need to be an effective father under the gaze of a system that has ‘got his number’.

I reflected on my commencing each new interview not really knowing what to expect, and always quizzical as to what I would find. The story of Ross and his family was one woven with contrasting extremes. His philosophy on it all was neither profound statement nor cliché platitude. He simply said: “It’s just the way it is, I suppose.”

## Hannah's home

Just as Ross was reflecting "I do have my moments with her, but she's a pretty good bloody kid", in bounced the fresh faced, smiling Hannah, perhaps looking slightly older than her chronological years - an observable or perceived discrepancy? She relaxed on the floor, a breath of energetic life in a room in which divulged secrets hung in the air, tangible only to those who had exchanged them. Ross offered to leave me chatting with Hannah, his parting line designating his contribution: "A load of rubbish." I negated this self-deprecating statement with my appreciation, and colloquial wording to the effect that personal experience is legitimate, and as such, not subject to a confirmatory grade.

## This is your life

I turned my attention to Hannah. With little hesitation, she began:

*People always say, what's it like living with cystic fibrosis and stuff, but I suppose that that's what I've always had. I've always lived with it, so if I didn't have it, it would be weird. Do you know what I mean? So like other people's lives, they're not in hospital all the time and stuff like that. But I've always been like that and so it doesn't affect me like people think it would. Everyone says it would be horrible and stuff, but it's my life and I can't really change it.*

There were steps, however, to her assuming this eloquent resolve:

*I can remember when I was at school and I was little, and I hated it because little kids can be cruel. They don't understand about the medication and all that sort of stuff. I remember when I was in grade one, there used to be the guys that would like bag me out because I had tablets and stuff. And I was like, yeah, it's pathetic, but ... that used to upset me when I was little. That's about all I remember.*

I wondered whether such peer response affected that little girl:

*It did a bit. In grade one it did. Then I realised that it doesn't matter what they say.*

The effect was more than just upon compliance with medication. The obvious fact that she had enzymes and they did not initiated an awakening:

*I knew that I was starting to realise that I am a bit different. Before you start full-time school, you're the same as everyone else. And then you start school and you realise that everyone's different. But I was more different. I had different things to deal with. It was hard when I started but it's all right now, even though I don't go to school.*

### **Exercising independence**

So difference would seem to be conditional and measured in relation to everyone else. It is also confirmed in clearly demarked zones of treatment such as physiotherapy, an uncomfortable encumbrance invested with the time perception of "ages" that unpleasant activities attract:

*I used to have to do physio on the physio table and my Dad will do it, you know, percussion and stuff, but I hate that. It hurts. Even if you do it lightly it hurts my bones and stuff. I don't like it at all. And it takes ages. So for physio, instead, I'm meant to use flutters and all that sort of stuff, but I don't use them either because I don't think they work. I just do lots of walking and go to the gym, things like that, cardio workouts, to get my heart rate up, and stuff like that. Most of the time, during summer and stuff, I'm not sick at all. But in the winter I need to do excess physio and stuff, when I can.*

But physiotherapy was fast becoming an outmoded activity, superseded in Hannah's programme by the oft-mentioned gym, visits there, I observed, being multi-purposed:

*You do your running and your jogging, that's all cardio for my lungs; and the weights are just extra, I think. But the cardio is the reason I'm going. Well, that's what the doctors think. But, yeah, it's helping me lose weight, so. The only reason I would go is the weight.*

Where previously physiotherapy was a mandatory process done to Hannah to keep her deviant body under subjection, she had now discovered gym, a domain wherein she

had assumed control, the results of which were tangible in her body's response, displayed in its adjusted boundaries and shape that pronounced she was winning.

There is also a hint that the little grade one girl who decided: "it didn't matter what they say" may not be so sure now that she is 13 ½:

*I want to lose some more weight because my friends are generally around 45 to 50 kilos. They're skinny.*

### **Weightier matters**

They also do not have a chronic life-threatening illness. But for those who do, there would seem to be intermittent occasions of assessing various risks and arbitrating for oneself on a basis of how much one will permit the disease to be centre stage. Conversely, a decision is made to sideline it - and future prognosis - in favour of conformable participation in life that is happy now.

Hannah was well aware of:

*Dieting and stuff. I'm not meant to with CF, but oh well, I've never had a problem with my weight, holding it, keeping it the same. When I was little, I used to be overweight. They never admitted it. I was like a big rum ball. My sister used to call me "veg", because I looked like a potato, because I was round. Once I got on the scales at the doctor's when I was like 12, and he said: "At least you're not as overweight as you used to be." And they'd never admitted it before. But I knew. I think I'm just two kilo's above what I should be for my age group. Because I'm 56 kilos. I'm 163 centimetres tall.*

Hannah had it well calculated, her body numerically bound, not a novel concept in a world of forced expiratory volume in one second, quantified survival years, and regular weigh-ins at a clinic that had officially confirmed her to be overweight. Maybe there is room to be blasé, take a calculated risk, when death is on one hand a surreal concept, but on the other, one that has seen the removal of one of her parents with its daily patently evident consequences. It also delivers odd benefits wherein:



*A lady in, I think, Sydney, and her daughter had cystic fibrosis and she died, and now she's got money and she wants to help someone else; and so she's going to pay for [gym membership] for me.*

How does a young girl deal with the fact that someone else's mother stood *locus parentis* in a provisional sense, paying to aid the warding off of the disease from which her child died - the selfsame one which you harbour? "I just have to write a thank you note," she told me, a process to which those with CF become accustomed, the cost of the gift accruing in value until the ultimate, most personal is delivered.

### **Dictation**

It was obvious that Hannah had considered her disease status, and the impact it has had upon her life:

*I don't want to let it - I want my health - of course my health dictates what happens in my life, but I don't want it to change everything. I still want to be able to make decisions about what I want to do. Instead of having people say, you can't do this because you're too sick. It's annoying. With school and stuff, I couldn't go because I was getting really sick and everything. That was both my Dad and my decision, to stop, but it would have been nice to keep going. But it was getting really hard. There's other things where it dictates my life, whereas what I wear. Things like that. Even if I think it's a hot day, and my friends are wearing skirts and stuff, if I go outside I feel the cold really quick.*

### **A friend indeed**

While friends had exerted a notable influence in areas of body size and the cladding thereof, Hannah valued her friends as important:

*I think they are to most teenagers. That's what I like doing, spending time with my friends and reading. I really love reading. My best friend I've known since grade three. Olivia, I only met last year, she's also one of my best friends. My other friends that I don't hang out with all the time, most of them I've known from primary school.*

Friendships and schooling changed dramatically at high school age, when Hannah began home schooling:

*I probably see my friends just as much now because when I was [at school] I was sick, so I wasn't seeing them. But now I'm seeing my friends every weekend and sometimes days after school when I can be bothered. My special friend Nicole, we used to live like a street apart, practically. But now she lives over there still and we had to move here. I don't mind. We still manage, because we just meet each half way, like at the hospital. It only takes fifteen minutes. So that's all right. It's not like we live in China or nothing. Some of them find it difficult to understand. My best friend Rachel, she understands because her mother was a midwife and a nurse, so she's really good with it. Other friends find it annoying, I think, because I make plans and then I get sick, or I'm tired, or something like that. And then there's things like, everything, really. It just annoys some people, the fact that I'm in hospital and it's harder to see me and all that. So, yeah, pretty hard for them.*

"And for you Hannah," I thought. The conversation flowed to relationships of other kinds, as Hannah painted into her description other key players in her world.

### **Family focus**

It was interesting to see how she portrayed her father, now that I was privy to his rendition of family dynamics. Issues such as his drinking and her resultant actions she elected not to disclose. Rather she characterised him, as 13 ½ year-old girls are wont to do, as embarrassing:

*I get really cold and stuff and Dad's always like: "Oh, you're going to get sick because you're not dressed warm enough." And that's annoying. And, in front of my friends he's like: "You'll get a chest infection. You'll be in hospital. Put something warm on." That's a bit annoying.*

Hannah placed their relationship into a context that, while not entirely peripheral, was certainly in balanced context with others in her life. She was keen to tell me about her various siblings:

*I don't get on with Donna at all. I just think that she's a complete dum dum. She's ruined her life completely. She's got her own problems of course, but what she does doesn't fix them. And then she does things like demands money, like I save my money for whatever I want. I mean, she's 18. You're an adult now, Donna. Chris's a bit better. I mean at least he's trying to do something in life. Donna and Chris have always been popular. Chris is really popular and up himself. It's cool having a popular brother and sister.*

Her only reference to her mother was when decrying the lack of baby photographs featuring her:

*I don't have portraits or anything done. No, because I was with Mum so I didn't get them. Dad did them for Donna and Chris and not me. That really sucks. It would be cute to have baby ones, like they have babies in the pots and stuff. They look cool.*

The “heaps - 55 or something” - x-rays that she has had are not in quite the same league, being the accurate medical capturing of her over the years, but void of “cute” or any endearing emotion on behalf of the eye that lined them up. “Mum” would appear to be relegated to another realm, almost existing in another lifetime.

### **A wider circle**

It is the people who have actually participated in her life that Hannah featured, a large contingent being medical carers in various roles and situations:

*Cheryl (nurse) and everyone remembered me when I was a toddler in the hospital, but I don't remember anything until I was about six or seven when I was in hospital with tonsillitis once, and heaps of bad flu's and stuff. It's sort of weird, like, people in the hospital know me from when I was little, but some of my family members don't. When you think about it, it's weird ... I don't know, it's pretty cool. None of my friends have nurses who all know their name and stuff. I walk through the hospital and all the cleaners and all the food people and everyone know me. Everyone says: “Oh you know everyone!”*

Such was not the case during her hospitalisation in another city:

*The first thing I said was: "I want to go home." It was sort of like up here you recognise people and it makes you more comfortable, but down there the nurses were completely, like they didn't have a clue who I was, or about my history or anything. Like I had the doctor down in Emergency, he didn't know me. Whereas if I was up here, they'd know about me.*

This seemed to be more a comment of annoyance than despair, spoken by an old trooper who clarified it thus:

*Some people find it scary when they have to be in hospital. Like, they are going in and they don't know anyone. I don't have those problems. I'm just so used to it. It's nothing different.*

### **Hospital holed-up**

Hannah continued with her impressions of hospital:

*I know I have to be there to get better and all that. And I don't mind the people so much. It's just the whole atmosphere of when I'm there I'm always sick. So it doesn't make it a good place. It can be really frustrating when you're waiting for test results and the doctors have got them, but they're busy and they can't come and see you, and all that. It's annoying because, like, I want to be at home. Like, I want to go to town, or my friends are going to the movies or something, and that sort of thing. And then there's the other side of it, where you think, if I'm sick, I don't want to be at home, where I can't - if I get really sick and no-one's here, it's not really good.*

While Hannah perceived hospital as a friendly place, it still had a negative connotation - the fact that being there means you are sick. Life on the outside continues on without you, because, despite their visiting, friends have the liberty to drop in and leave, not tied to a place by intravenous lines or negative pathology.

### **What's in a name?**

She returned to her consideration of personalities, citing Richard, a physiotherapist, as being "cool." Names are important to this young girl, who drew a contrast with:

*The Melbourne ones, they're all right. Oh, they're very impersonal, because they see so many people, and they like forget your name. You sort of understand. I mean they've seen so many people. They all start to look the same. When the specialists come over, they just ask a bunch of questions and read your notes from previous months, and do your weight and your height and lung function and everything like that. "Everything is really good at the moment, apparently." That's what they say. "Next."*

Hannah obviously preferred the local clinic, inserting the names of not only staff but also other patients - "cystics" - with an affection and familiarity not usually conferred in a treatment setting. But this is usual for Hannah, to come to a place where the faces are well-known, their welcome warm, their reactions predictable, and their being there consistent. Sounded a bit like family to me.

### **Back to the future**

Discussion of the past and present flowed naturally into Hannah's contemplating her future. Seeing school as an important link to achieving goals, she decided:

*It's hard getting motivated, but you've got to think, if I don't do it, I'll look back when I'm twenty and I'll wish I had've. That's what everyone thinks when they get older. They think, I wish I'd paid attention in this or that or whatever. And I want to get into uni and all that sort of stuff, so I'll try.*

After this somewhat mature out-looking, I was waiting to hear what she would want to study at university:

*Nursing would be cool, because, I mean there's all other stuff that would be cool, too, like be a fitness instructor and all that. But I reckon nursing would just be fun. You'd get to see all the different people from everywhere and they're all different. So it would be cool. But it would be hard with CF because you get sicker from everyone, and that's what everyone always says, but I don't know; I don't want to let it.*

Returning to nursing, she continued:

*And it's really interesting to learn about all the different diseases and different everything; about the human body and all that, because it's an interesting thing.*

So she does not feel negatively towards the human body, the housing that on her part requires so much maintenance. She deemed it “interesting,” along with a knowledge of other diseases, as though placing hers in an arena with others may in some way make it more usual, being part of a group; not as bad in comparison with others. On the other hand, interesting may simply be the result of intimate familiarity with the disease process that has rendered a competence and corresponding confidence in an area of study.

### **In time to come**

“I want to have kids. I love kids,” she bubbled, placing these progeny in the same breath as: “I love cooking and stuff. I reckon being a chef would be cool.”

Ideas flowed thick and fast as she brainstormed the time to come that by description was rendered possibility.

Her gaze then lifted to places further a field as she mentally skimmed the planet:

*I want to travel Australia, but I don't want to go to America or anything. I reckon the world's just stuffed at the moment. It will probably be different when I get older.*

*America doesn't really appeal to me, except for their clothes and stuff. None of the other countries really appeal to me except Australia, because I'm comfortable with Australia.*

Her around the world tour thus ended, Hannah declared: “I want to succeed in something,” and indeed she will do, if being motivated and personable are anything to go on.

## Ian and Max

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In form and feature, face and limb  
I grew so like my brother  
That folks got taking me for him  
And each for one another.

-H.S. Leigh, *The Twins*

The next family was the only one I would meet who had more than one child with CF. Thirteen-year-old Ian and his seven-year-old brother Max had seemed keen to contribute when I met them at the CF clinic. Ian had been sporting a very trendy gelled and spiked hairstyle, and was lapping up the attention it generated. However, on my arrival at their home on the designated morning, their mother, Julie, apologetically told me that he had now decided that he would rather not participate. I was not surprised that Max, five years his junior, likewise declined. Having reassured Julie that their changing their minds was by no means a problem, I invited her to unfold her tale of having two children with this disease, and all that meant for her, and her husband Neville - who declined to participate - and their 15-year-old daughter, Cindy.

### Julie

How had life been so far for this family in which two of its five members had CF? Julie was to be speaker, a role she assumed because, although Neville:

*Does help, it's different for a dad isn't it? The mum is usually the main carer of children, so the mum tends to have the responsibility of a lot of things. I accept all that, that's fine. If I'm not happy with anything I'll let Neville know. We talk a lot about things and he's very good with the kids.*

This was the first reason she was chief reporter. The other was that Ian and Max's withdrawing meant that the insights she ascribed to them were as viewed through her eyes.

Unknowingly slipping into the pattern that all parents in this study had followed, Julie launched into the diagnosis drama that began with a baby boy who “just didn’t look right.”

*I didn't know Ian had CF when I was having him, and he was born with a blocked bowel. He was born with heaps of problems, and there was something about him. When he was born I looked at him, and I just had this feeling he wasn't right. I don't know why, I mean I was pleased he was a little boy because I'd had Cindy, but I don't know, there was just something about him. He just didn't look right to me.*

For this mother, there was the body seen and the body perceived, because, although the evident body initially appeared usual, it did not perform according to anticipated specifications, as:

*He started vomiting all this black stuff up. He wouldn't feed. He was like he was full all the time. They tried to unblock his little bowel and nothing worked. Dr. Davis was up here then. He was really wonderful, wonderful bloke. I said to him could he please check him out, I didn't think that he was right.*

Julie seemed to have initially enjoyed positive interaction with the medical professionals in her new baby’s world. This was suggested by her overwhelming praise plus the fact that she felt confident within that relationship to speak her concerns, rather than being subsumed in the doctor-knows-best, I’m-just-the-mother role, but one she did subsequently assume:

*I think he could see that I was a bit concerned about him, so he checked him out and he said, no, he seemed fine to him, but he said: “If you would like I'll get Dr. Martin to come and have a look at him.” I thought well, there's nothing wrong with him, I'm just being silly.*

It was in response to Julie’s concern, rather than any clinical signs, that the doctor reassessed Ian, offering a second opinion. This understanding yet efficient medical routine caused her to review her disquiet, relabelling it “nothing” and herself “silly.” But just as well she did not give up there:



*He came up and he took one look at Ian. Next thing we were down in the special nursery with him, and I had to sign forms, and he was really ill, and we had to go to Hobart.*

Julie squashed all the action into one swift sentence, not unlike how it had seemed to her at the time. She and her baby were swept up in a flurry of activity in which Ian was changed to a different nursery, then to a different city, the fact that he was not right ratified by signatures on forms.

And so it was that Ian took his first flight:

*When he was only two days old, we flew down to Hobart with the Flying Doctor, and he had a bowel operation that. It was just a nightmare. It was just absolutely - I just couldn't believe it was happening.*

The nightmare continued, as Ian's bowel blocked again three times, necessitating:

*Four big bowel operations in a matter of that many days. It was an absolute nightmare because we'd leave him, and I'd feel that he was going to be alright, and we'd come back up here, and we'd pick Cindy up from her grandparents, and we'd come home, and there'd be a message on the machine, you'd better get back down here quick smart, we don't think he's going to make it. So we'd have to pick her up again and drop her back.*

A picture of Julie and Neville driving up and down the highway came to mind. She concluded this part of their story with: "He didn't have a very good start - he's a little fighter," a fact that applies to all members of that family, and one that, I was to hear, had characterised their CF experience from then on.

But for now, a little boy and his traumatised body that had endured the rigors of repeated surgery, was now subjected to a battery of tests - an onslaught that could have been minimised:

*They tested him for everything. They thought that he had a bowel disease to begin with, so they tested him for all those related things first. I think the sweat test was the last thing they did, and that was, you know -*

### **Kissing cousins**

A sweat test confirmed and brought to light not only Ian's having CF, but that someone else did too:

*I found out - I have my first cousin who's been sick all the time. I remember him when he was a sick, white, real sickly looking kid, but I never knew what he had. When we found out what Ian had, cause I told my mother and my mother then rang family in Melbourne, and that's what my cousin had. If I would have known what he had and understood that it's something that's an inherited thing, I could have said to the doctors: "This is in my family, do you think this is what he's got?" I mean it would have saved such a lot.*

Thus it was that a distressed grandmother phoned interstate relatives, believing she was conveying shocking news of a disease she would have to explain, if not spell, only to find that they were well acquainted with not only the disease but also the associated trauma. Julie and Neville had just been through the gruelling pursuit of a diagnosis. A snippet of insider information could have shortened this process. Not telling friends was something Julie was to say she did, but family seemed a different matter, when their link with you was not cordial but familial.

What mental image and future projections were then conjured up in the minds of these parents, when the only available template was the "sick, white, real sickly looking kid"? How ever did this distraught pair superimpose it upon the form of their new son?

### **No idea**

As Julie added:

*I couldn't even say the name let alone spell it. I had no idea.*

I wondered how motivated a mother would be to learn the pronunciation of words that she does not want to utter, because with the speaking comes the framing of reality. Likewise the spelling thereof, as letters grouped in a sequence one has not yet grasped, deliver tangible evidence, and convey a disease title that once known is not forgotten, and often uttered from now on.

Name known, they now had to learn about this disease. Julie told me:

*When he was born, only every year, a team of doctors would come over from Melbourne and they would go to the hospital here, and they would also go down south.*

The importance and value of this medical expedition was obvious in Julie's tone. Here was an information line, I imagined. She continued:

*But they would come over in June.*

While this was a set appointment in the busy team's schedule, it was no good for those like Ian, who was:

*Born in June and so I missed out. So it was really, well, I mean Dr. Martin didn't specialise in that. So it was do what you can, and trial and error, and we experimented with this and experimented with that. So him and I were together to try and get him right, get him going. For that first twelve months I had no idea of anything about it or how to care for that person.*

"No idea" was a state in which Julie remained for the first year; a time during which she negotiated care with a doctor who seemed to have only *some* idea. She reported the process of care in quasi-scientific language imbued with hypothetical concepts such as trials and experiments, rather than sound practices of care. Her discussion at this point lacked the assurance that may have been theirs had they been able to invest the doctor in their scenario with an expert's badge.

## **Wrong size**

They were joined in their exploratory venture by the child health nurse:

*My clinic sister was actually wonderful. She got in touch with someone from the CF association for me. She did a bit of scouting about and found out that there was a group and I rang them up, and all the information that they were giving me was about adults. There was nothing on babies, how to care for babies and young children. I found that very difficult. It wasn't easy. It was really difficult. You just had no idea what was going on or how to care for him properly.*

This nurse sourced information from experts - those who lived with CF and their families and carers. Their focus appeared to have been on adults, an understandable one for people who initially may never have imagined that that would ever be the case; their supplying of such literature possibly being an attempt to display the potential that now existed for Ian's future. Julie, however, was fostering the growth of a baby-size body in the present, a time in which sufficient unto the day was the evil thereof.

## **And baby makes two**

There were other incidents in which secrecy was the option of choice:

*We didn't tell anybody that I was pregnant with Max until - well I wasn't going to tell anybody at all if we weren't going to go through with it. It was just between Neville and I.*

The first recipients of their supposedly good news were Neville's parents, for whom, perhaps, the ordeal of one child with CF was enough particularly when your side of the family has made no progenitive contribution thereto:

*My mother-in-law said: "Oh my God how can you do that? How can you bring another child into the world with that?" That upset me, I didn't think she'd react like that and I said: "Well look, this is Neville and my decision, and this is what's going to happen, and we want this baby and that's it."*

Meaningful others, who were supposed to be excited at the prospect, instead withheld their blessing, as it were - a reaction for which Julie was unprepared. It also alerted her to the fact that these grandparents may also not react positively to the child already extant:

*I don't want you to be feeling sorry for him.*

This admonition, however, went unheeded:

*One day she said to Ian: "You poor little thing, what you're going through," and this, that and the other and I said: "He's not a poor little thing." Things like that really annoy me. He's not a poor little thing, he's alive and as well as he can be. He's lucky and he's a lot healthier than a lot of other kids.*

And it was at this point that Julie drew upon the dynamic of comparison with 'there's always someone worse off,' a transaction in which several parents in this study engaged, as they mentally assessed CF against imaginably worse conditions - as far as they could, see, anyway. This process would appear inane when compared with the one in which they were to subsequently indulge, one in which CF itself was the standard against which their assessment was made, utilising criteria with which they were only too familiar indeed; intimate knowledge being rendered by an eight-year acquaintance.

Julie described feeling shocked when Neville declared:

*I think we should have another baby. I thought, oh no I couldn't go through all that again, no, no. I'm happy with what I've got. I'm thankful that I've got Ian because there were several times that he nearly died ... My sister had a couple of babies after I had Ian and I used to watch her and think, oh my God I just would love to have another child and I really envied her. But I thought, no I just couldn't, but the more I thought about, I thought, Oh how do you reckon we'd go? So we talked about it at great length first, and we both decided we wouldn't have it if it had CF.*

What in one instant is a desired baby and another child, becomes an “it” that these parents would not want if the genetic allocation at conception invested yet another offspring heir to the hereditary disease. How easy was her sister’s procreation in contrast with a longing that was tempered with life and death.

To have another baby was merely the first in a succession of decisions. The doctor:

*Suggested I go to Melbourne and have these tests. They do do them in Hobart, but he said they don't do as many down there, and he thought that maybe the results - not that they wouldn't be accurate - but he just thought that I would be best to go to Melbourne because they're doing them everyday.*

Are the Hobart “they” wasting their time, I pondered, or will practice make ‘better’? Such opportunity will evade them, however, if candidates like Julie continue to be shipped offshore. This was one test that did not need an errant result. All the best-laid plans, nevertheless, can go well astray, as Julie continued:

*He had to be ten weeks, anything under ten weeks they really couldn't give you a definite yes or no, and I thought, that's no good to me. I've got to know. How can you decide what to do when you're unsure of the results? So I went and it was very unpleasant. It's like an amniocentesis, but they take the tissue instead of fluid. This massive big needle goes into your tummy: I saw it on the monitor. The baby, I could see.*

Now it became a baby on the screen, like footage of a hopeful starlet auditioning for a part - because the person viewing in this instance had the power to offer a starring role, or to dismiss them with the ‘don’t call us’ option. There was much at stake, not just the lives of Neville, Julie, Cindy and Ian, but the little form that faced her that day. Could they choose to inflict it with the life of potential trauma like Ian? What sort of guilt would daily present itself as a result?

Conversely, are all the considerations negative ones? What of the pleasures of life with their first son, as opposed to living with a disease? And what of the distinctive depth of experience and interaction that may elude those families not so encumbered?

The images and emotions that cascaded through Julie and Neville's minds may not necessarily have been of the pessimistic kind. She knew that they had a son, not a disease with a child attached; and one for whom the luxury of the 'will we or won't we' choice was not an option.

I could conjecture living with CF. She knew it, and all it involved, and appreciated the good times with attendant treasured memories. Could she deny another child - and this family - those?

They had time to think about these things because after two weeks, no results had come, and Julie was now twelve weeks pregnant, and was:

*Starting to get a bit worried, like I'm thinking this little thing's developing inside me and I just don't know. So I rang the doctor, and he hadn't heard anything, and he rang me back, and the test was contaminated, and so I had to go back, and I'm thinking, oh my God, no, once was enough.*

Another flight, another journey to a timeless juncture of viewing a body within a body, stacked together like babushka dolls, as a medical jury once again seeks a verdict of guilty or not guilty before recommending the penalty.

*So I psyched myself up, right, I can do it, I'm going to do it again. I went back to Melbourne and I had it done again, and I came back, and I knew as soon as I fell pregnant actually that he had CF. I just thought there's no way I could be that lucky. I was sixteen weeks then when I found out and I asked the doctor what happens, like if we want to terminate and he said I'd have to give birth to it. I thought, oh my God. I thought, I can't do that, no, no. So he's meant to be. It just never went according to plan, you see, and I just thought, well that's it. It's just the way it's meant to be.*

And so it was that "it" was granted a reprieve, and became Max.

### **Poor form**

Julie continued on, now leaving the past and its problems, which had been superseded by those more contemporary and immediately pressing, particularly for Ian. As an

adolescent, he was grappling with not only awareness of bodily issues, but also of a disease that meant his development was not keeping pace with those around him, and with whom he sought to belong. Julie considered:

*We've had a lot of problems with - not problems, I shouldn't say problems - he's found it very difficult. He's not growing like his friends are. He understands his condition more, as he's getting older he understands more. He asks more about it. He doesn't cope with it at all, which has been difficult. It's difficult to keep positive.*

Positive would be a dynamic that I imagine it might be difficult to engender when the yearning for a matured body is tempered by not only its tardiness, but also the increasing realisation that having CF may mean an early foreclosure upon tenancy, and consequently not long to enjoy the fruition of this maturation ordeal.

Julie reflected:

*No, he's been very depressed. His self esteem, his image of himself is very low, doesn't think he's going to be around for long so why bother having a goal in life. It's pretty heavy when you're only 13 - it started last year.*

Julie continued on, her story painting a diverse picture from the image I had initially gained when first meeting them at the clinic, when for Ian, a trendy haircut and cool demeanour were obviously part of a veneer behind which to secrete his struggles. I understood why he would not have wanted me, the researcher, to delve past the boundaries he had erected.

Fortunately, his mother recognised her son's plight, and, as Julie relayed:

*When the Melbourne doctor came over, I had a talk to him on my own, and I told him I'm doing all I can do, but he needs something more. So they organised for him to go to Melbourne, and they worked on him physically and mentally. We went in February this year and he had what they call a tune-up, because his health suffered as well. If you're not happy with yourself, low self-esteem and don't feel confident about things, I mean your health suffers as well.*



Relationship is an intrinsic feature of adolescence, being a source of affirmation and, in the case of behaviour, moderation. An even more influential one might be that of the relationship with self - in Ian's case, its quality being reflected in the poor performance of the body in which he was housed. Thus was his form threatened on two counts - by self-image and the disease that contributed to its downturn.

### **Social circles**

As a result of Ian's first hospitalisation, a new arena entered their realm of experience:

*So him and I went over [to Melbourne] for ten days. He was in hospital for that whole time. He met other kids with CF in hospital, which was good for him because he kind of got that way that he thought, and I think that he probably still does think, that he's the only one that suffers this thing, and he thinks that he's the only one that has to have the medication and the physio and all these other things.*

This was an interesting comment, in light of Ian's daily companionship with his brother, and I would have presumed the camaraderie born of commonality of disease status. But Max was, after all, brother and family - one group in which a developing adolescent frames a concept of self. The second, outer circle of identity, and perhaps gaining greater import for this 14½-year-old, was that of his peers. Amongst them the perception of being the only one is stark indeed, manifested in body dimensions not attained and activities declined, which cannot be explained because the reason is *entre nous*. Thus was the pressure and process of adolescence compounded. Besides, he was worrying for two.

### **Not to worry**

There was, however, someone concerned for him. As his mother considered:

*I don't know, I worry about Ian more than I do Max. I don't know why but I just do. Max's very different natured than Ian and I think each step that Ian takes is a big thing for him. I don't think I'm going to have those problems with Max.*

Max, on the other hand, enjoys the privilege of the traveller on the blazed trail, who, oblivious to the pioneer's extraordinary efforts, heeds the guide's protective warnings

with a sense of 'it's always been like this', the route being mapped out before he was even born. How different Max's life would be without Ian the forerunner brother, but then, that concept could apply to any family members, CF or not.

Julie continued to contemplate Max:

*He doesn't like school, never has, probably never will. But he gets on well with everybody. He's a likeable little person and I don't have any problems with him. I think he thinks everybody's got the same thing. Because he's got Ian and they're very thick. Ian dotes on Max and if Max doesn't have any medication out: "Come on Max, gotta have you're medication, gotta keep yourself well and healthy." So he's good for Max because Max will copy what Ian does. So I really honestly think that Max just thinks that everybody's the same.*

And what of their older sister, Cindy? Was she, then, the odd one out? How did Max accommodate her? Of course:

*She's a girl. Yeah girls don't have these things.*

The conversation returned to Ian's struggles, in which his moving into yet another group against which to assess himself seemed to be just in time. Those with CF he met in hospital were not a kid brother, but those his age, or thereabouts, and therefore, suitable mirrors. In the context of relationship with these others, in this case, those with the sympathy of an insider understanding, Ian could perceive a reflection of himself, as opposed to the constant deflection of who he was when with outsiders.

Amongst the uninitiated, there would always be a part he could not disclose, because no matter how well intentioned the separation between this person and his disease, it negates the fact that CF is an intrinsic part of life.

### **New kid on the block**

Julie continued:

*It was good for him to see that there are kids that are in hospital, and they're in hospital all the time, and he has never been in hospital. It was the first time in February. He didn't want to go but I told him he would come, and he's pleased now. It was good for him to see what goes on, and there's a lot of people out there that want to help. So it was good, and he came back and he was a new kid.*

New context, new image, new understanding of CF. One wonders what images these boys had before that? I use the plural here, aware that any image modification in Ian would have a natural flow on to Max, their lives being chronologically separate and yet disease-wise, a common experience, one in which Ian appeared to carry the greater load.

Julie continued to extol the results of the Melbourne expedition, conveying her patent relief at the welcome breakthrough, which was:

*Just amazing. His whole outlook on things. It's still not like probably I'd like him to be, but I tell you it is a hundred percent better than what it was - his whole attitude. I mean, he would never talk about what he was going to do when he leaves school. He's a lot more positive about things, and he's talking about what he wants to do when he leaves school. He's talking about, he's saving up money to buy a car and they're all good things. And he's put on weight, and because he feels so well it's kind of turning his thinking around.*

Because this was not always the case.

### **No future in this**

So, back to home, back to the group in which he exists daily. Ian had discovered a fourth group, as Julie described:

*He had a little girl friend in primary school. She's a gorgeous little thing and he told her that he couldn't go out with her anymore because he had nothing to offer her, and he had no future, and she'd be better off to go out with somebody else. I mean, it's pretty deep stuff. For him to be thinking of that ... He doesn't want to get close to anybody, which is another thing that he has.*

Deep stuff indeed for a 13-year-old, the notion of no future being over shadowed by the contemplation of the long-term prospects of relationship at that age. Was such seriousness precipitated by the concertinaed concept that future appeared to be?

His mother conjectured:

*I don't know what it's like for him. I know when he's not well and then I do things I need to do to help him through that, but I don't know what it's like for him. To be him and to cope with all that. And he can't tell me because I think he thinks that I have enough to worry about, I suppose. I think that's what it is. He can't tell me things. He goes along his little merry way.*

While Julie could relate her experience, encompassing that of her whole family as she did so, her perception of life as Ian knows it remained but vicarious supposition. She conferred it with a nuance of merriment, a figure of speech as there appeared to be little jocularity, however.

### **In the know**

I was glad to hear that Ian did have a close friend:

*He has a best friend, and they've been best friends since playgroup, and they've been in the same class every year. They were both in grade eight together, so they're going to be in grade nine together. So that's really good because Ian really needs him, and James is such a wonderful friend. He'll go and stay with James but he won't go anywhere else. I think cause he feels comfortable with James, and his mum and dad know all about him. He's quite happy to take all his gear, all his medication and they don't make a big deal about it.*

There must have been a time when Ian and his parents took a calculated risk in allowing this friend and *his* parents to be in the know. They obviously responded appropriately with a type of 'your secret is safe with us', an invaluable acceptance. Thus their house became a secure domain in which "all his gear" could be displayed without shame, explanation or fear of rejection. How vulgarly cumbersome such equipment is, when you are desperately, adolescently trying to blend in.

These dynamics did not operate in other situations, however. Julie reminisced:

*Last year in grade seven, they had a camp. Ian didn't go. I think he just didn't want the kids to see, cause he would have had to take all his gear, and I don't think he wanted the kids to know all that. Even though I'd organised with the teacher to do it in a private room, and no one would have seen him, and probably people would have just thought that he was gone to the toilet, but no, he just didn't.*

Here was a space that was decidedly unsafe, one in which devious manoeuvres may have to be employed in order to maintain the deception of being just one of the gang. Who wants to lug “all his gear” to camp - the ultimate exposé? The risk of rejection would be too great.

At this stage, equipment and medication represented a daily, arduous compliance, and a set of objects that could be shunned with disdain, and concealed. One day, I mused, they will be viewed with a different perspective, almost seen anew. They will be the means whereby another day is counted off, and the only way to have enough breath to make it to the letterbox - and back - an ordinary activity that for those like Tim, further along in their CF journey, posed inordinate risk indeed.

Could Ian's attitude of concealment have been fostered by Julie's own outlook?:

*I don't tell anybody that he's got CF. I never have, because I found that the people that know that he's got a problem, I don't know, they change. They tend to be a bit different towards him, like a bit sympathetic. Sympathy, we don't want that. When I go up to school with Max and with Ian, if they get into trouble, I don't want them treating them any different than anybody else, and I don't allow that here. They're the same. They get into trouble like anybody. So just because they've got this little problem, doesn't give them an excuse to get away with things. I've made that quite clear and that's fine, they accept that.*

Any smattering of sympathy would not only highlight the “little problem” that takes some effort to conceal, but would also undermine the inordinate effort both she and her boys had expended to attain a superficially normal status.

## **Educating school**

While Bob's school had initiated the education of the matron, Julie had taken on this responsibility for her sons, as she explained:

*The teachers that we've had up there at school have always been wonderful. I've gone to them at the beginning of the year and explained to them. I think Ian would be the only one up there. He was the only one at primary school. Max's the only one there. They're very understanding, eager to know all about it, which is good. I make it my business to go up and explain things, and I take them little booklets and all sorts of things, and I say Ian frequently visits the toilet. These are things you're going to have to let him do. A number of times it's just not convenient but he's just got to go and also with coughing, he's just going to have to let him cough. I have said to Ian if he coughs too much - because there are times when he coughs and he kind of gets a bit out of control, you know, he's cough, cough, cough, cough, and it's kind of like he's going to vomit or something - he leaves the class.*

School was not, however, always idyllic nor pleasant. Some teachers may not have been so keen to receive the information that a child would be exhibiting these symptoms in their class:

*We did have one teacher when he was in grade five, and she was very cool and very nasty and made it very difficult for Ian. It was like she was the start of it, of him thinking that he was not worth anything. I honestly don't know, I mean he was responsible for his own pills, his tablets and any other medication. He was old enough; I left it in his hands. She didn't have to do anything.*

Was this teacher possibly relating to Ian with her own interpretation of preferring no sympathy, as instructed? Did Julie's rhetoric of "not treating them different than anybody else" translate into a converse reality? Either way, it was time for action again:

*I went to teachers and expressed my concern about my son that his health was deteriorating and if something doesn't get done about it he just won't be able to come*

*to school. I couldn't have anybody doing that to him. Isn't it terrible how protective you get? I was terrible.*

Once again, the woman who had dubbed herself “silly” when advocating for her newborn, now nominated herself “terrible” when interrupting the *status quo*. But Ian was “missing a lot of school” that year:

*I don't know what I'm doing to her Mum. She just won't leave me alone. She's at me all the time, and I just got that way, well look boy, you just stand your ground. You just say: “Well, why are you doing this to me? Why am I getting into trouble all the time? What am I doing wrong?” Much to my amazement, he stood up and stood his ground and she didn't like him questioning her authority. She didn't like that at all.*

And so Ian developed his self-assertive skills and honed his strength:

*But I think it made him feel stronger. I said to him: “You've got rights as well and if you feel that you're being unfairly treated, why take it all?” So much to my amazement he did; because I've told him to be like that because this is the only way that he's going to be able to survive.*

Survival is a skill that this young man needed to develop. Indeed, to simply survive is a status he will ultimately hope to attain.

### **Independent living**

A natural progression in parenting is the gradual relinquishing of responsibility to one's offspring, a process that for the parents of children with CF represents more than natural maturation. It is a progression that some have imagined may not have eventuated - a procurement of a future that other parents have as a taken-for-granted.

For those like Julie and Neville, it is also the releasing of the incessant care of the child's body, a double-edged process being both a relief and a risk - the child will assume more of the burden, but will they fulfil it with the rigour and passion of their parents? Said Julie:

*I've tried to encourage them to be independent and responsible for their own health, more so Ian than Max. Ian will get his own gear out, medication and things now, because I said to him: "Look I'm not going to be here for ever saying: 'Have you had this? Have you had that? Have you taken your pills?' I'm not going to be here forever." I mean there's going to be a time when he will want to move out from home and I'm not going to be ringing him up every day: "Have you taken your pills? Have you done that?" So he's a little bit more responsible for his own health, which is good.*

### **Just do it**

It was at this point that Julie's narrative waxed lyrical, as she sought to philosophise, and consider her outlook on life with CF:

*People say to me, I don't know how you cope and I say, well you just do. You do. I mean they're your kids and you look after them and that's it. You just do it. There's no, I can't do that, or how am I going to do that? You just do it. You don't even think of those things. So they're going well at the moment, which is good. And Ian is going well, which is important.*

She contemplated further:

*I like to be around people that are positive and make me laugh. That keeps me going. That's what I tend to need. I don't usually let things get to me. I usually sit down and work things out, and try to always look on the bright side of things. Even when Ian was really down and out, I was worried and very concerned about him, but I didn't let him see that, which is a bit of a strain in itself; but I'm very positive and try to keep him that way, which is the only way to go because if I didn't have that attitude, I couldn't look after them. I mean if I didn't feel positive about them and was always negative and thinking, you've got no future, and you can't do this and you can't do that, how would they be?*

And besides, her mind could run away with her, back to a screen in another state, where she had insight and choice; and even further back, to another baby, who, to her untrained eye, did not "look right". But for now:



*It was probably hard in the beginning but it's eased, so it's not hard. They're good kids. They're no trouble. They take a lot. They're very different. They don't complain about anything. They just go and have their needles and blood tests and all those things, and they seem to accept it all as being part of it, which is nice. They're very tolerant of things.*

While symptoms are kept at bay and finiteness of prognosis looms distant, life in this household could be considered 'normal' - for them, anyway. That families so situated strive for this everyday equilibrium begs the question of what it is. A redefined understanding is necessary for them because otherwise, how do those with CF know they have attained it? For Julie, it began with Ian's first days when he did not appear normal. In Max's beginnings, normal was under scrutiny, proposed selection to be made using it as criteria.

Conversely, might not the successful accommodation of the daily relentless regime of physiotherapy, enzymes and other medications achieve the unique normality of those living with CF, and for whom notions of life and death figure continually and familiarly on the horizon?

*And now I have two and life's the same as any household. We don't do anything different than anybody else really. Just that the boys need a bit of extra care, that's all. I'm positive, a very positive person, and we're learning with Ian. Because he's my oldest, there's been things going on with him that's prepared me for Max. Hopefully it will be easier for Max, when he goes through all these different stages.*

So for now, CF is somewhat peripheral, subsumed to a mundane "bit of extra care." The central character would seem to be Ian. It was his story really. That was how Julie narrated it, with a sense of this family and Ian. He is, after all, their prototype, and if they get it right with him, it will be okay with Max, the chosen one.

## Brooke

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Let it go. Let it out.  
Let it all unravel.  
Let it free and it can be  
A path on which to travel.

- Michael Leunig, *A Bunch of Poesy* [sic]

Squeals of delight and cries of: “She’s here!” greeted me at eight-year-old Brooke’s house. As Brooke had been relatively well, this was a family that was unknown to me. In fact, her mother, Liz, felt that: “She’s been well - we’re probably not what you need.” “On the contrary”, I assured her. She then felt free to talk about the experience that she, and her husband Garry, had obviously considered not medical enough. Brooke and little brother, Adam, then joined in enthusiastically. Interacting with them as they drew various pictures was a delightful and insightful interlude.

“Ask me questions because I don’t really know what my story is,” Liz began, the comment of someone who had not previously been invited to give voice to her experience. She had judged that it was not what I would want to hear, as it lacked the medical titbits that she imagined I might be seeking. Thus she rendered her experience invalid according to firstly, what she assumed I was after, and secondly, when considered in light of initial anticipated disease projections. Her family’s script had deviated from the first draft they had been given. As Liz was to reiterate: “She’s been so well ... She’s gone along so well it’s nice, and we’d like her to continue that way.”

## Liz

### Pale and wan

Despite being born in the mid 1990’s, Brooke’s tale was one of a baby who failed to thrive. Liz recalled their doctor being “unhelpful” at Brooke’s declining weight and increasing pallor. “Obviously he’s not our doctor now,” she quickly clarified, her short phrases sweeping away details of a long ten weeks of difficulty for this new

mother. It was a child health nurse whose experienced eye noted the discrepancy between the anticipated body size and the frail little baby that actually presented. Then paediatricians, tests and hospital entered - and complicated - their world:

*He did a couple of sweat tests, but they just couldn't get any sweat out the new way that they do it; and then she actually lost some weight. So he said he wanted to put her in hospital, and they did the sweat test the old way. So Friday they took the blood test as well, so obviously we had to wait over a weekend. But the sweat test came back before then, and said that she had CF, and the blood test came back, and she was actually quite anaemic by then.*

So for this family, while there had certainly been a feeling of uneasiness over their child's progress, it had not been accompanied by the traumatic episodes of bowel and stomach distress that other parents had described. Hence Liz's conclusion to the hospital story was tainted with an 'all is fixed' flavour:

*She was really good because we had to stay for the rest of the afternoon in hospital, to see if she could swallow the apples with the capsules in them. She was only ten weeks. Rather than the liquid, because the liquid isn't as effective and it can burn them, I think.*

This observation reminded me of Bob's mother describing the burning both she and he sustained because of his enzymes, which at that time were not available in any other form. Liz chatted on, finding that she did indeed have a story:

*And she was really good. She took the capsules and took the apple and was eating mashed food, and lots of it, by the end of the next week, and still breastfeeding really well. And she was putting on weight each week. So really that's the only problem we've ever had, was her failure to thrive. From then on in she's thrived and she hasn't had any.*

### **Just visiting**

Apart from the initial hospitalisation, Brooke's CF experience had been enacted in the arena of clinic, a place for those just visiting, or at home, where it appeared to have

been relegated to the perimeter of this family's horizon, priority being occupied by general parenting issues. Liz separated the two thus:

*Most of it is not even to do with CF in our family. It's all to do with -*

She trailed off. I wondered whether such discrimination is a luxury permitted only when there is a lack of obvious bodily symptoms and disease progression. Another contributing factor was Liz's philosophical stance of:

*I decided I wasn't going to let it rule our life. Everybody has got to learn that, like I say, life's life, and get on with it.*

### **Depressing news**

Had Liz's attitude always been so cavalier? As her story unravelled, she identified that she had been "really depressed" at the thought of maybe not having any more children. Likewise:

*Initially, I spent a lot of time with Mum, because you're just getting over the shock of it all. Just go and sit down there. Plus, at the start, I was paranoid to take her anywhere.*

This was the result of her fear of Brooke "picking up germs," but I suspected that refuge and comfort were not only for isolation purposes. This family required shielding for another reason, as the diagnosis of CF was:

*My first bad thing that happened to me. It was just having to learn to deal with grief and all that. But I think we're very strong because in the end I said, we're not going to go down this path. I'd rather go down the other one. And then after that, on top of that, she's been so well it makes it easier to put it in perspective. I mean it might be different if I had to spend a lot of time in hospital and all that, and readjusting back.*

The diagnosis of CF would have been a shock on several accounts. Firstly, Liz and Garry had heard of it but: "You have but you don't take in what it is." Secondly, CF as initially presented to them was not that of the 1990's, not the updated version of

current disease facts. They were given a picture comparable to that conveyed to Tim, Bob and Hannah's parents, one that was no longer a legitimate portrayal.

*The information we got in hospital was very old, and a lot of the nurses didn't know a lot about it. We got, from one nurse, that: "No, they can't do any sport, and they can't do anything." I was thinking: "Oh, no," because we're a very active family. So you do start thinking how it's going to affect you.*

Liz and Garry were not only presented with an inaccurate description in regard to a curbed lifespan. These condensed years were juxtaposed with the concept of a future in which an energetic family would have to accommodate a child unable to participate, those short years potentially appearing full of paradoxically long days. She continued her dialogue:

*A few nurses thought it only affected boys. I found that really funny, that they didn't actually understand the whole genetics of it. Even one of the physios commented that it was unusual it was a girl. And a lot of the pamphlets had them living only until a very, very, young age. So that was very depressing at the time.*

Thus it was that the knowledgeable professionals conveyed neither consistent nor accurate information to these parents, who initially looked implicitly to them for the delivery of presumed the current truth, not an outmoded version thereof. This then became another time in which depression featured in their living with CF.

Myths and mistakes were subsequently dispelled by the paediatrician who recognised the information as "really old", and contemporised their experience by connecting them with others, arranging for Liz to "meet someone else who had a little baby with CF around the same age." While she was relieved to be able to discard erroneous information, it had threatened to erode the tentative trust she had thus far established. She resolved:

*I basically decided that I would read as much as I could. As [the doctor] said, most of the time you know more than he does in the end. So I read everything, even from nurses' and doctors' stuff, not just the stuff that they want the parents to hear.*

Liz had realised that not only was there old and new as well as true and false documentation, but also information intended for ‘them’ or ‘us’, a divide on one side of which she was not happy to sit passively. Her quest for current information saw her:

*Get a newsletter from England, just CF News. That’s just free. It’s good because it has lots of little letters from people who have got CF, and also older people, and also they have the research and stuff like that. But that’s from England, so it’s all English based. And I joined the Tas CF thing. They’ve got a newsletter every now and then. Also the New South Wales newsletter.*

Liz collected news from a variety of sources, its encouraging quality infused with subtle stagnation:

*Not a lot’s happened, in a way, since Brooke was born. You know, when she was born, they thought that maybe a cure was probably only five years away. It’s probably the same distance away now and she’s eight, so they haven’t really sort of had a lot of new breakthroughs since then.*

Although Liz presented a Brooke who was “really good” with “no problems,” the image overlayed a somewhat conditional foundation that stretched into a future full of options that parents do not usually have to factor in. For this family, there does exist the latent negative prospect of Brooke’s CF worsening, with an untimely demise. Likewise the converse could present, in the form of the elusive cure that in this case has evaded the projected five years, being now three years overdue. Always numbers. Always counting. Always time accounted for.

### **In isolation**

While others through their ignorance had excluded Liz and Garry from information, there was another dimension in which Liz felt cut off. That was geographical placement, wherein separation by a stretch of water in a comparatively small community engendered a sense of isolation. She considered living on an island a disadvantage:

*Only if the CF people didn't come over, because they are definitely a lot more informed, because they are in paediatrics for one particular area. So they tend to know what they're going to do.*

And if the team did not make this biannual expedition?

*If they didn't come over, I'd go to Melbourne, not to live, but I'd go to Melbourne for her updates and all that because, I think we do a really good job for our size, but we're just like a small country town in respect to what's happening in Melbourne. I think in some ways it's nicer because over there, there's a lot more CF.*

### **Free supplement**

Her attitude of active pursuit extended to nutritional supplementation. She smiled as she recalled:

*Brooke had the best concoction, because she used to eat lemon juice mixed with fish oil mixed with avocado, and she loved it. Mixed with vitamin E liquid. [The doctor] was really good like that. I'd just go and say I want some vitamin E and he'd go: "Yep, not a problem" ... Actually, it was funny because a lot of the things that they were recommending in the last few years at the hospital, which one of them is vitamin E, and they've also brought out a multi-vitamin aimed at just CF, and another one with something else, I've always had her on anyhow.*

### **Under normal circumstances**

Liz was very conscious of cross infection, particularly at CF clinics where:

*Most of us don't mix. You just wouldn't mix with the children that had CF. Isn't that terrible?*

On the contrary, under the circumstances, it would be sensible. Besides, as Liz added: "I don't make it my whole life."

Rather this family have situated themselves, and their child, in a framework of others who do not have CF, but seem willing to learn. Depicting Brooke as social and "she

goes to other people's places," Liz described other parent's willingness to have her overnight. "All the parents have actually asked me before I've had to tell them" she told me regarding Brooke's requirements, adding: "She just has a really normal life compared to some."

This family have thus far incorporated CF into their way of life and constructed normalcy around it:

*But we've been very lucky regarding, kind of, put it in and have a normal life on top of it. Which some people don't like you to use that word normal, but like I say, it is different. People don't like you to say their children, or compare another child and say normal, but if she's got CF, she's got CF, you know. If someone hasn't, they haven't. That's life.*

### **No hiding**

School likewise seemed to be an arena of community acceptance:

*Her kindy teacher had already taught someone with CF, so she knew, and she even said: "Do you want me to help with antibiotics?" And I said: "Well she's not on them all the time." So she knew what she was talking about. They already know they've got someone with a special need cause the kindy teacher's already passed it on. They've all been really helpful, but they haven't had to do a lot because she's not not well.*

Liz then enunciated what I had already gathered may be the case:

*We don't treat it like you shouldn't talk about it, and we don't treat it like it's something you should be ashamed of, or whatever that attitude is that some people have. So she wouldn't reflect that attitude. So she hasn't had any problems at school or anything like that. She may probably have some problems with Adam but it will be nothing to do with CF.*

This statement on problems was not made in ignorance, because Liz was well acquainted with the fact that such is not always the case for all. She told me:



*You hear of some families and their children have trouble because they get picked on, or whatever. She doesn't have that trouble. Well she hasn't at this stage, and most of her friends think it's pretty fascinating that she can actually take all those capsules in one mouthful!*

All seemed to be going smoothly at this time of Brooke's life, when her mother could categorically state, emphasised by a double negative: "She's not not well."

### **Family ties**

Unlike earlier families in this study, left with only conjecture and piecing together anecdotes and supposition regarding the origin of the disease in their child, Brooke's was a family who knew:

*My Dad's the carrier, because when we found out, they would still gene test the parents. And then they stopped it, which I think is really silly because I think you're better to eliminate which side of the family. So my sister got tested and at the time they said that they would test Mum as well, and Mum wasn't.*

It was then that Liz mentioned the unknown genetic luggage of Garry's family. While he had been implicit in our conversation, her nominating him now highlighted him, and I wondered what his place was in this family. Liz depicted it thus:

*He actually is really good, but he doesn't actually - usually I take Mum [to clinic] because it's someone outside our immediate family, because then I'll show him. And a lot of the time it's just work time, and since we've had Adam, he actually has a day off a week to look after him while I go to work. But like, he does physio, so it's not just me. We do everything pretty much half and half because he has to on his days off, and on the other day I'm at work, he finishes work early. So he'd be responsible for whatever. He knows how to do it. He just does what's needed. He wouldn't have ever read anything, though. I do the reading and the talking and whatever, and he just does what, he just follows up.*

Hence his preference for Liz to speak with me on behalf of this collaborative partnership.

## **Independence day**

Their participation in treatment was changing, as:

*She's got to the stage now in the last 12 months where she does a lot of it all herself. So it's really only down to us doing physio for her now, and probably just checking that she's taking everything that she should take, as far as remembering her vitamins and stuff.*

In deciding to "make her responsible for nearly everything," these parents were engaged in a process of gradually relinquishing care and custodianship of Brooke's body to her, in harmony with an earlier resolve that she would be "independent."

## **Quite aware**

At this point, Brooke wandered into the conversation with: "What's independent?" Liz, however, needed to finish the question of heredity by telling me about the difficulties of being pregnant with Adam, and their relief at finding out that he was "not even a carrier." Brooke echoed her mother: "not a carrier," endowing the word with a familiarity of both concept and usage that would have been extraordinary for an 8 ½-year-old - usually.

I reflected upon the poignancy that such words as 'carrier' and 'cystic fibrosis' should be in a little girl's vocabulary. Not only that she should be so adept with using them, but that they should be in reference to her self, her body, and comprehended better than 'independent.'

CF would seem to steal more than chronological time from its incumbents. It robs younger ones of the fantasy of immortality - that elasticity of time wherein it is forever until lunchtime, and next Christmas feels so long away.

## **One day at a time**

What else did Brooke have to tell me? As a natural progression in the interview, Liz was bringing to a conclusion the story she was not sure she had, one which had seemed fairly routine until a recent cough:

*A couple of times in the night, but that only took a couple of days to clear up. Until then the CF specialists say that her lungs just look like any child her age. So that's why I said we'd probably be boring.*

I assured her that her tale had been anything but tedious. She responded by waxing philosophical, dredging up the 'there's always someone else worse off' dynamic:

*A little friend in hospital at the moment got hit by a boat and that actually makes you stop and think. I just, no, we just enjoy life. I mean at least you're not going to look back with regret. I mean every now and then –*

Liz had an acute awareness that:

*I can't control life. You can only control certain things in life.*

For this one who vacillated between no story and one that was supposedly mundane, her tenet for living was summarised thus:

*You've got to just live one day at a time, and what's the point of grieving over something that hasn't even happened yet.*

## Brooke's beliefs

When I shall die,  
I shall do it myself.  
Nobody shall do it for me.  
I shall say,  
'Fin, stand me up',  
and I shall look  
and lagh [sic] merry.  
If I fall down,  
I shall be dead.

- Fynn, *Mister God, This is Anna*

## This is your life

Brooke had spread out on the table a freshly executed drawing of a remote control [overleaf]. She explained:

*It's a remote, your life. Looks like a channel and that's just play, fast forward, rewind, stop, and beeping, and backward and forwards, and up and down.*

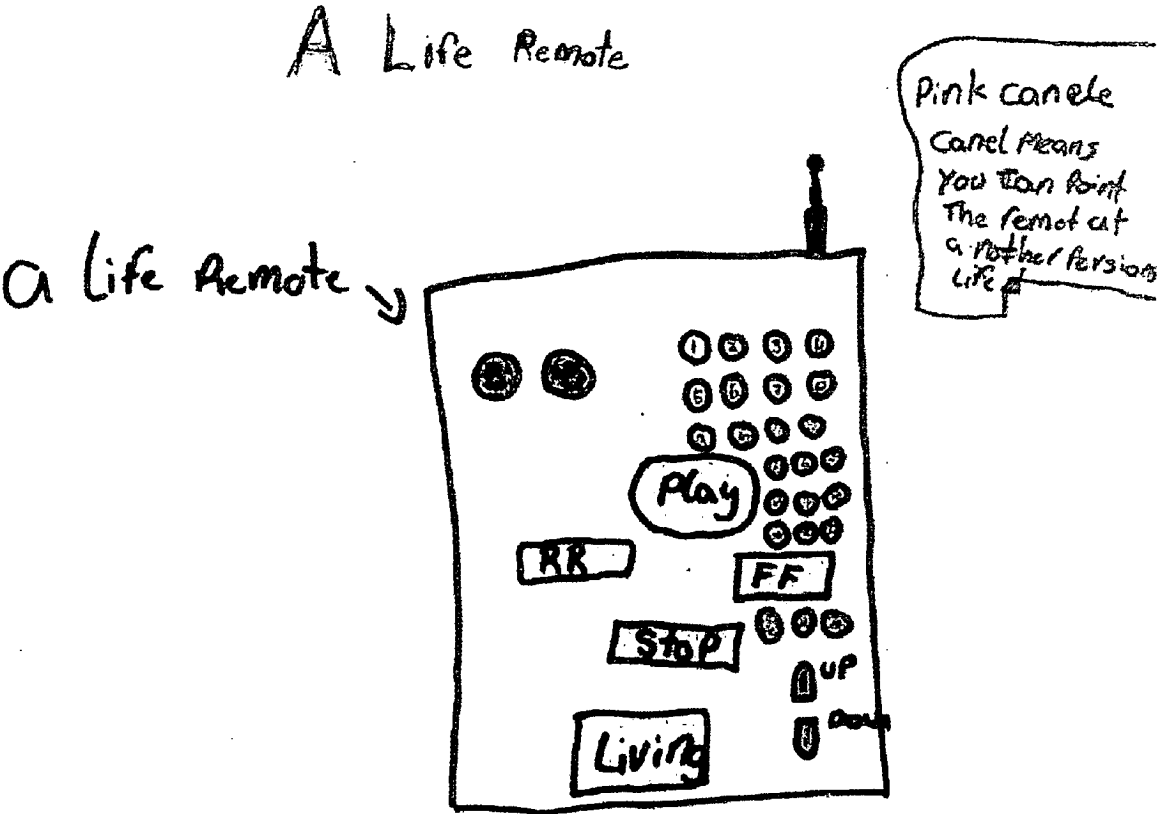
Eager fingers indicated the various buttons representing time dimensions well beyond the present. She had not only envisaged past, present and future, but had contemplated the possibility of rerunning both time and experience. In glossing over the potential of the stop button, it being a punctuation between fast forward and rewind, she highlighted the rewind function. I asked if she would want to do that, to which she replied:

*I don't know. Although if you did rewind it and then fast forward it back to where you were, you could see what was happening again, and it would be different to what's happening now.*

In what ways, I wondered, would Brooke desire difference? To go slower, perhaps:

*That's backwards and forwards and this is like slower. But you are still living it as you go. Do you know what I mean?*

Figure 1



Of what images did her conceptualised future consist? If she had legitimate ones, where would this little time traveller choose to stop the fast forward process and land? This is probably not such a binding question when built into this idealistic mode is the provision to rewind or actually stop. Any future depiction of a utopian life in which CF plays no part should not be derided, because for a generation of CF children sometime there has to be a time when scientific pursuit ensures that dreams do come true.

### **Daily dread**

But time was up for such conjecture. Brooke landed squarely back in the present, launching into her impressions of daily physiotherapy:

*I don't like doing my flutter. I only like Mummy doing physio on me, only her. Daddy hurts. Mummy, remember I hurt my tummy when Daddy does physio? When you do it, it doesn't hurt as much.*

Those strong paternal arms probably exerted a better long-term therapeutic result. However, the body of the future can be an elusive concept for a little girl who just knows that today "it hurts," a state of immediacy wherein CF at this stage does not portend a framework of symptoms on which to construct any potential perception. What a perverse state of affairs.

### **Amongst friends**

The other daily reminder to Brooke that CF is in her life are the incessant enzymes. She considered having to take them at school with other children watching:

*My best friends and the friends I've known for a while don't, but I don't like having to explain it to everyone.*

Explaining was not only difficult, but also subject to appropriate timing. Brooke recalled that tomorrow was the first day of the new school year, one on which life was complicated with a new class, different friends and a teacher who may not know that you have something extra to show and tell:

*Mummy, you said you weren't going to tell Miss Robertson tomorrow. You were going to tell her after.*

But the kindergarten teacher from a previous year had passed on the information. That was one thing sorted. What else did Brooke have to consider? She returned to her enzymes:

*I started those white ones. They were disgusting. Started those white ones with the red writing over it. They weren't as nice. They were bigger. Now I don't think they're big. I think they're small compared to the other one cause if I had to swallow six, probably I used to swallow three and then swallow the other three, now I can scull twelve down.*

I commented how impressed her friends must be at such an achievement. "I'm not impressed with it," she retorted. Such a feat may have been precipitated by an absorption problem of a differing kind - that of assimilation into school routine, acceptance conferred by adoption of prevailing group norms. Hence the dilemma she described thus:

*Cause it's too hard to sort out my - no, wait. What I used to have was a little container separate to my lunch but all my other friends, and a lot of people at school, had their morning tea with their lunch, and they knew just what to take out for morning tea. So I wanted to do that as well. My mum can't put cap - oh she can now, cause I've got a lunch box. I can put one up there and one down there.*

Otherwise, one is in danger of being left behind, missing out:

*By the time I've sorted out the capsules out of that little container, everyone else would have opened theirs, from the canteen as well.*

Such planning. All this seemed so complicated for a little girl amongst others who simply eat their sandwiches and play - a tempting option, I would have thought.

Existing friends appear to be a haven in which one does not need to disclose. So is spared the declaration that moves CF from a mechanical, subconscious routine of medication to a highlighted abstract disease concept that has to be explained, rendering both acquaintances and the sufferer conscious of it. Brooke reiterated:

*Well I don't usually tell my friends I've been with for a couple of years, because they know.*

### **An active life**

Racing along to another topic, Brooke relayed her physical activities, including cross-country - "I came second and third" - and family activities involving scooters and the dog. She explained:

*I do a pretty good job. But the dog gets in the way because as soon as he gets a fair bit in front of Mum, he wants to go back. Yes I'm fit. Mum says I've got very nice legs. I like swimming. I do basketball at the YMCA.*

Proudly Brooke extolled the achievements of this body that performed as she wished; and at this point, was in sync with her demand upon it. It was also fulfilling appearance expectations - at least her legs were.

### **I'm busy**

Brooke chatted on:

*I like going to the clinic, especially with Nanny, because after that I get a lot of food. Cause at the clinic they've got that little café thing at the bottom, and Nanny buys me lots of food from there when I finish, if I'm a good girl. I like going there cause they ask me questions and they're not good. I don't mind going as long as Adam doesn't come, because he always wants me to go and play with him, and I'm busy, and Mummy tells me I have to.*

For Brooke, her CF medical care was equated with three-monthly clinic visits, hospital being the setting in which such outings occurred. They were punctuated with set tasks and routines, the interception of questions by some anonymous 'they'



interrupting the process to which appropriate compliance resulted in the reward of novelty food. It was not a time in which she relished including Adam, who not only wanted to play, but also had to share - both the accompanying adult's time and the post clinic goodies. Besides, Brooke recognised that it was not a time to play. This was business, about which she will always be "busy."

## Toby

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Our worst private fear was about to be plucked from dormancy in our subconscious and planted into our real lives.

- Bryce Courtenay, *April Fool's Day*

The value parents placed upon not only my research but also their contribution to it was brought home to me upon arrival at five-year-old Toby's house. His parents greeted me sitting ready at the dining-room table, his dad Pete having arranged with his workplace to be home early that day. Following their very candid recounting of life with their only child, they pottered around 'busily' nearby, as they had clearly prearranged, while Toby, an obviously prolific artist, produced several drawings. His mother, Kate, keenly invited me to stay and share their Chinese takeaway meal. At the end of my visit, this family saw me to my car and waved until I had driven out of sight.

### Kate and Pete

Separate interviews were not a concept that even occurred to these parents, dual participation in life being their philosophy. Without any hesitation, they inclined towards the tape recorder with a demeanour more reminiscent of those who do this often and who want to broadcast their message far and wide. Pete launched in:

*I suppose we're better off to start with the problems we had with Toby, that he's had terrible reflux, used to be at 6.30 of a night and he would scream himself stupid for an hour and a half. He would get that red in the face, his mouth just seemed that big that there was nothing we could do with him. You couldn't console him.*

### No milk today

I remember thinking that this was a familiar story. All had not gone well from the start. Kate recalled the failure of her initial attempts to establish a satisfying breastfeeding relationship: "We just couldn't connect at all." Her statement was

suffused with the disappointment that her body refused - or was it that Toby's rejected - her proffered sustenance and corporeal comfort.

But these were motivated people:

*Kate was great at keeping records and used to write down his feeds, and how much he had, because we thought the clinic sister would be interested.*

Such rigorous recording must have been no mean feat when the baby was being fed "fourteen times a day", which translated into "every hour and a half, to two hours" - time they remembered well, time which was paradoxically lost yet seemed unending.

The feeding process necessitated them taking turns at night when, as Pete described:

*He'd be crying or screaming. He'd want his bottle. You'd warm the damn thing up. You'd give it to him. You'd probably have to change him. You'd settle him down. He'd sleep for an hour and then start again. You'd take turns.*

After three months of this, their high motivation was whittled down to despondency, because, although they were super-organised, conscientious and aiming for the optimum baby's first year experience, Toby was unable, by virtue of his body, to comply with reciprocal participation in this relational plan. Said Kate:

*I honestly don't remember that three months. I can remember thinking, what the hell have we done? I really wondered what on earth we'd done because I didn't know what was going to happen.*

Kate and Pete floundered, wondering, because they could see no cause, just hideous effects. Were they doing something wrong? Blame cannot be apportioned to a 12-week-old boy. But if you have done all that you can, and everything still goes wrong, what indeed is "going to happen"?

They persevered, watching the videos on reflux supplied by their child health nurse, who nominated Toby's condition "nothing." His parents, however, were unable to

realise the happy ending that such footage conveyed. Pete called a halt: "This has got to stop." The uncertainty certainly did:

*We got a phone call from the local paediatrician and he said: "We've picked up something in the screening test (this was at 4 ½ months old) and we believe he might have CF. Don't read any books, don't look it up, don't do anything. Bring him in for a test."*

Without hesitation, they quoted the date of diagnosis - a perverse anniversary when a disease masquerading as "nothing" was identified. Their initial reaction of being unable to "believe it" did not belie its existence. Their doctor offered a tempering clause, as Kate recalled:

*"Mind you, we think he's only a carrier because we can only see one gene" - one of the defects.*

Was that somewhat confusing statement the result of indecision or did it reflect a lack of understanding of CF on the doctor's part? This tentative withdrawal of diagnosis still left a set of unaccounted for symptoms. The doctor asked how Toby was. Pete was quick to reply:

*Well he's good considering we'd never had any other kids and we didn't know. And maybe if he was the second child and you'd had one ordinary kid, I suppose, it probably might have been easier, but only having one, you don't know.*

I recalled a similar sentiment being expressed by Tim and Bob's parents - the naivety and subjectivity of normality, attended by a subconscious sense that what they were experiencing was not it.

Even as these parents talked, the trauma was still not quite over. Kate had more:

*Remember we took him to the doctor who put him on that brown funny stuff, in that brown bottle, that was supposed to try and help him? It was some outlandish horrible muck. We went back to him a few times, then we thought we were killing him so we*

*didn't go back to him anymore. We were trying everything, to try and work out what was wrong, why he was screaming so much. And you'd just come home and I walked out the door and I just screamed. I was just in tears. I said: "He thinks there's something wrong with our baby."*

There ensued a sweat test and a positive diagnosis, and yet another family was precipitated onto the merry-go-round of information procurement, a ride, it seems, that is taken alone, as others cheer from the safety of *terra firma*, calling out indecipherable words and reappearing with definite regularity as the roundabout spins. All the rider can do is hang on, because there is no getting off until the time is up.

### **Old news**

Pete did not speak very highly of the doctor who first enlightened them about this disease that as Kate said she had "probably heard the name - maybe - but didn't have a clue what it meant." They were understandably distressed when the doctor, a self-professed "expert on CF":

*Told us he may not be likely to make five, might get to ten. Most of these kids, because he was so progressive, got into their early twenties perhaps, with a great heap of treatment, and his old professor that he used to work with lost all his kids by twelve.*

As a result of this news, a feeling of impending loss was initiated:

*You've got this child there and they're saying - they're taking him away, like he's not going to last the distance. I spent nearly my whole life in tears in those months because I just said to Pete: "What sort of life are we going to have?"*

Words consist of letters and comprise the currency of verbal communication. They can also redefine a little boy's position in life, from being at the beginning of many years to being further along his indeterminate continuum, and seemingly drifting from his distraught parents, whose own life plan has to be reconceptualized because of "what sort is it going to be."

To be told such news - to imbibe the words - was one thing. Believing them was another, a further process made difficult by continuing conflicting information, as Pete recalled:

*It was all part of the acceptance deal too, because the clinic sister was saying: "Oh they're wrong, they've got it wrong." She was a wonderful person, but of course, the ones that she saw when she was nursing them in hospital were on their last legs, and she's looking at this big bouncy boy, and she said: "Look they've got it wrong. I wouldn't listen to what they're saying. I wouldn't do what they say."*

She likewise had an understanding of an older version of CF, and as I was to find out later in the interview, in this she was not alone. Subsequently, I was not surprised when Kate confessed:

*Well, we were terribly confused because we're a bunch of mugs who really didn't know down from up, and the doctors do this, and she's saying, oh get a life. We're saying, we'd like a life, but we really didn't know what to do.*

Pete returned discussion to the paediatrician, with whom he seemed to have unresolved issues:

*Now I don't know a lot about the legal system, but if I knew what I know now, he wouldn't be going anywhere, because my lawyer would just make mince-meat out of him. I'll never forgive him. He didn't know what he was talking about. He should never have discussed CF because he was just a fool. We rang [our GP] the day after and she said: "Thank God you've finally been told." She knew from when Toby was six or eight weeks old that he had the possibility of CF. And they'd been waiting for him to tell us.*

Just as had been the case for other parents I had spoken with, Kate and Pete had trusted the health care professionals whom they consulted, because they presumed that these people would be as conscientious in being well acquainted with the latest on this chronic and life threatening illness as they would.

### **In isolation**

These parents were not only isolated geographically because of living on an island, but also by being situated in an outlying coastal area, where a dearth of contemporary knowledge imposed an even greater isolating effect. Pete remembered being told they would have to go to a larger, tertiary centre several hours drive away because “there’s no-one here.” For yet another family with CF, the necessity to travel often and elsewhere had begun, and flight was another dynamic for contemplation.

### **Play the fool**

Kate confessed feeling “total fools” and “stupid” until they got the recommended treatment and feeding regime right. Was the assumption that they should comfortably deliver such foreign care expertly one that they had made, or was it a subtle implication in the delivery of instruction from those to whom it was familiar? Kate and Pete berated themselves for getting it wrong, rather than viewing that as understandable considering that, as Pete explained:

*We were in total shock. We didn't know what to do. We were looking for guidance. We were looking for someone to tell us what is the go and what is going to happen. We didn't know.*

Despite more people to confer with at the larger centre, they were still plagued with uncertainty, initial trust having been broken by conflicting facts and attitudes. They were left with a flimsy foundation upon which to construct an accurate understanding of CF, a foundation which hampered interaction with more medical carers, and their building relationship with their baby son. Pete recalled their flight reaction of a differing kind:

*All I wanted to do was pack him up and take him to Disneyland so he had a bit of a life. That was my feeling. It was just awful. You know, you thought, well what on earth's going to happen?*

What information had they received at the larger centre that left them still not knowing what was going on? They implied there was more of it, and that it was more accurate. They needed, however, an interpreter to understand it, as Kate told:

*And the doctor, nice enough fellow, but was talking over our heads. We had no idea really what he was talking about. I suppose you need to talk to people in layman's terms, being aware they are totally shell-shocked and they really haven't got a clue what you're talking about. You know, just try and get us organised with what we needed to do.*

These exhausted parents who had had no peace night or day for weeks, did not immediately comprehend the aetiology, intricacies of current treatment, and stark prognosis of a hitherto only "heard of" disease. They were not "stupid," Pete reiterated, they simply did not realise just "how much shock we were in."

Kate continued to blame herself for not immediately grasping the fine timing of food and enzymes; the issue of getting his feeding right being one at which she had not felt successful since he had been born, despite desire and meticulous documentation.

### **Insightful quandary**

It was many months later that another set of carers entered their domain:

*It wasn't until the Melbourne doctors came over - Toby was about 12 months old, might have been 16 months old before the Melbourne people came over - and they just - and we felt about this big, just didn't have a clue - all of a sudden it clicked.*

"Finally," I thought, sensing their palpable relief. However, no matter who or where, in the end, Pete decided:

*It's all you can do, just get on with it. I mean, you're on your own basically. They can talk as much support or whatever they like, but I mean, you see the people from Melbourne, you might see a social worker for 20 minutes, sit there and try to psychoanalyse you once every six months, and how you handle it.*

While they did come only twice a year, Pete felt the Melbourne team offered stability, another source of legitimate information, and specialists in their - and his - field:

*I like the Melbourne one [clinic] but I think the local one has different ones all the*



*time when you turn up. Every time you go up there, there's somebody different, and they don't really know you and you don't know them, and what to say to them. We don't really know what they're trying to do. Are they checking up that we're looking after him? The one from Melbourne's good because if we say we want this information or that information or whatever else, she'll send us stuff, post it over; but I suppose it's because she works with the clinics and she understands exactly what's going on, whereas the ones that are here don't work just with CF kids.*

He contrasted the interstate outsiders with the personnel they encountered locally. Initially, he recalled:

*It was like everybody had an opinion and we didn't have a clue what we were supposed to do. There was no centralised care for someone getting the right treatment, the right advice.*

How could these parents know what the right thing was if there was no:

*Consistency in care, I mean how many dieticians have we had in the last two years? If I have to go through another day of his capsules again, I'm going to scream.*

Such would be the cry of a frustrated father who felt trapped in perceived inconsistency, mediocrity, and lack of prerogative to go elsewhere.

*People move on, we know that, but there must be something that - obviously there's a greater attraction on the mainland for younger people to go, and more dough, and all that sort of thing, through mainland hospitals. It is really hard, like this lady who was a dietician, she said: "I'm going, I'm off to Sydney. You'll have to find somebody else." Well we just can't go off and find somebody else.*

Meanwhile, Kate and Pete contended with the dynamics of fragmentation and parochialism as evidenced in this small, island setting. Pete summarised it thus:

*There's all this political stuff going backwards and forwards. That's probably the big thing - that the south's better than the north. The north's better than the northwest,*

*and all this sort of garbage. All the ones that are saying that ought to be at least staying in these areas and having a look and see. It's crazy. We should all be working together to help these kids. Damn the politics.*

I appreciated the sentiments expressed by these parents whose experience had rendered them a more extensive view. Politics, however, cannot be readily discarded because, as Kate said:

*The problem is you're dealing with people, and you're dealing with people's lives and some people can't - through work or money or time - get their kids to [the main north and south centres]. It's really, really difficult.*

Indeed it is, and often proponents of change become discouraged and move on to lands where life is easier - or more in harmony with their views:

*We've often talked about whether we should move or whether we shouldn't. I think you've got to strike it with the right people.*

### **Inconsistency**

For now they elected to stay. Still dogged with dubious information, Pete was keen to tell:

*We went to one clinic and one of the nurses said: "When did he catch it?" We just sort of looked at her. We thought she was having fun with us and then we thought, oh this builds your confidence. Deadly serious. What could you say? We were astounded. Oh beauty, we're going to go far here.*

They described times of "still searching and battling for information," with Pete considering that proffered by an uninitiated GP thus: "Well that information is not good enough for a kid with CF," particularly when it is yours.

He considered other parents of a child with CF:

*Most of the parents that we've spoken to when we go to CF things, most of them don't*

want to know. They want to know what they deal with today and how they get through tomorrow, but as far as long-term and whatever, they just don't want to know. They're just not one bit interested, are they? Whereas we want to know that if we do this today, he gets through three tomorrows. They want to know if they do this today, he makes it to tomorrow. We're not interested in that. We want to know that whatever we can do now that's going to get him past 30, past 40, whenever, we're going to damn do it, and that's it. There's no worries about that. So you need to have as much information and knowledge as you possibly can to modify your ways, to make it best for him. And there's no good just dealing with one little thing at a time because I believe you can't focus and understand by just knowing little bits. Little bits are no good to me. I want to know it all. I want the whole thing.

So Kate and Pete continued the pursuit of current knowledge in its entirety, as though a complete and contemporary grasp might render access to prospective, potential time, which, if they could in any way help it, they wanted to extend. Kate reported their present GP acknowledged:

*You know a lot more about CF than I do. I saw CF kids when I trained, and then you don't see them.*

Hence their "scouring the bookshops" when Toby was subsequently diagnosed with asthma. This led to their discovery of mega dose vitamin therapy, with Pete confessing:

*We secretly started. We didn't tell the doctors. We thought, oh well, and it was just magic wasn't it? He'd been cough, cough, cough, cough, and everything just stopped, didn't it? We just couldn't believe it, and so we continued on with these doses, and then we sort of confessed to a couple of doctors that we'd started on these vitamins and [they said] we were wasting our time and our money. Then all of a sudden at the clinics, vitamins is the way to go. It's what they're supposed to have.*

I recalled Brooke's mother describing a parallel experience of using discredited therapy that was subsequently normalised, rendering relief that one is no longer utilising therapy which other parents are not, and also a certain authentication and

kudos attached to knowing the latest already.

### **Out in the open**

Secrecy did not shroud Toby's essential medication, however. On the contrary, as Kate explained:

*We are so lucky, because look at him - who would know? Not a soul in the world would know there was anything wrong with that child, would they? Apart from the fact that people think we're slipping him drugs when you're sitting in the coffee shop. We give him his capsules freely so he accepts them freely and it's not: "Take this before someone sees you," because then it's sneaky and underhanded and his life does not deserve to be sneaky and underhanded.*

Kate recalled comments from people in supermarkets who would stare in response to Toby's coughing, some actually saying: "That child ought to be home in bed." Such quips do not dissipate easily because:

*It's hard, it's like you're not looking after him and yet we would do a million times more things to look after him than a lot of parents have to do.*

An amount of 'more' also applies to Kate and Pete's financial investment, their grocery bill being "horrendous," apart from "food and medicines and things."

### **Why us?**

Their vigilance thus far had not been without personal cost. Kate calculated:

*We're both on blood pressure tablets and we're both fairly stressed because of it. We haven't gone out much since he was born. I mean, he's only turning six in a couple of weeks, and how many times have we been out? We've been out about four times I reckon in six years, haven't we?*

It meant that these parents had sacrificed their own relational needs, these being subsumed as time was redirected from it to Toby. They were influenced physically as well, as their bodies attempted to absorb corporeally the stress that existed not just on

one level.

Kate and Pete's united front had required much negotiation and compromise, and loss of a personal kind. Pete confided:

*Probably something too, you tend to lose your individuality with it, I mean you can't - unless you're fairly selfish - you can't do things on an individual basis. You can't go and have a wonderful sporting career outside of your work, even if you're terribly good at something, if your child's sitting at home and your wife's got to look after him because they're sick most of the time.*

Kate very candidly confessed:

*I certainly got resentful, I really did, and I used to feel that I was - I suppose when he was home with me, all the time that I was home, he was home. He might not be well. Pete'd be off at work and you know, you'd sort of have to be doing things and physio three or four times a day and you did resent it. Why us? Why is this happening to us? How many times have we said that?*

Pete proceeded, telling me about further sacrifice they had had to make, particularly involving their farming dream. "Not another one," I wanted to say, remembering Bob's parent's similar relinquishing of a vision:

*We really had to change our life, I mean, we had a beautiful little farm up behind the town. We sold that and moved here, which gave us no weekend work at all other than a bit of garden. We modified things. I sort of play a bit of golf maybe, but Kate and Toby have got clubs and they come. We can't really do things individually unless one of us stays home and the other one goes out. We're doing things together and the family that plays together stays together.*

So with some moving and some modifications, Kate and Pete constructed a new life. Kate concluded:

*Because we have to be so focused and committed to doing what we've got to do for that child.*

### **Family**

They needed to be a united front because "every day to day, week to week, you're really on your own." This social isolation was particularly evident in Kate's perception that:

*It's been really tough, and I don't feel we've had a support base of family and friends either, really.*

Not a stated withdrawal, rather it was something "you just pick up."

She added:

*I consider my brothers and sister and I to be fairly close, but no one wants the responsibility of looking after him. I thought one of them might like to baby-sit one night while we went somewhere, but nobody wants to know.*

These parents were familiar with difficulties, Pete describing their coping thus:

*It's not a battle but a lot of the time you find you're fighting things uphill. You go along quite happily and then all of a sudden you get some obstacle you've got work your way around.*

### **Hospital visit**

One such problem was Toby's only hospitalisation so far - a traumatic experience. They struggled not only with the stress of balancing both of them working and being vigilant at his bedside, but also with the discrepancies they saw between the rigorous care which they did at home - "we sterilise everything all the time" - and the differing standards employed in the acute setting. They were only too aware that this would probably not be an isolated admission, and wanted it to be the least distressing as possible for Toby. Included in this desire were his veins. Pete explained:

*It's not a kid with pneumonia you're never going to see again. He's probably going*

*to be in there six months or three months later if their health's not good, but you want to try and look after the veins as best you can. A few things we weren't happy with is probably just general hygiene with changing masks and washing masks and that sort of thing. We were told you had to do this and then you can see the health people not doing it.*

This confusion, together with some difficult interactions with medical staff left them resolved:

*We swore from then on there's no way that child's going back to hospital. It's been touch and go a few times, but we've done whatever we can out here to keep him here.*

Besides, this resolve was tempered with the “worry whether he is going to come through,” said Kate.

By way of a footnote, Pete added:

*But we found the nurses very good. They were very caring in looking after him. They were extremely busy too. We could see how busy they were, and we tried to do as much as we could.*

### **Daily duty**

Physiotherapy Kate described as something:

*“We take extremely seriously. He gets a bit sick of it at times.”*

I wondered whether they did as well. On further reflection, she added:

*Life's certainly been better with him since, I suppose, the last 18 months or so, since he's been a bit older; and I suppose, probably because he was so well during that time, we relaxed a bit. We still were rigorous with his treatment and he has to have his physio and he has to have his nebulisers and everything - no quibble about it. That child has to have it whether he wants it or not.*

Built into this strong resolve were the beginnings of a simultaneous process in which these parents would gradually relinquish their control in what they have conceptualised as step one in a process about which I had no doubt they would have read. His mother continued:

*Most time he just has it. He doesn't worry too much ... Every now and then he wants to do it himself. "I'm doing physio myself." And you're trying to do the physio and the little tap, tap, tap, getting his hands in amongst everything. We're going to talk to the physio and get him onto something like that so he can do a bit of stuff himself, just so that he's a bit more in control of it himself. So that's our next step, to do that.*

### **Initial insight**

So while Toby was the main character in this family's drama, and central to all its activities and relationships, did he assume this role in happy oblivion? What did he understand about a disease that had dictated their lives? Physiotherapy precipitated an awakening, as Kate described:

*He came home and said: "Oh Mum, all those kids in my class, they're all going to get sick." I said: "Why are they going to get sick?" He said: "They don't have physio." I said: "They don't need to have physio." "Why not? You have to have physio. They don't even need tablets, Mum." He was just horrified. He had no idea that he was different, no idea at all, and we don't want him to feel different.*

What a revelation - that not everyone in the world has physiotherapy. Not every child anyway, because obviously adults do not, otherwise his parents would have participated in the four times a day ritual, rather than being just the instigators.

### **Seeing is believing**

Even though they had told him about CF only a few months before, Kate considered it to be "water off a duck's back" at that time, adding:

*It wasn't until the CF week the other week, in October, that he really understood. Like he used to ask for some money to take to school for Jeans for Genes Day cause he wanted to give some money to the sick kids. That gets you in the back of the throat.*



The process of enlightenment continued. While Toby's school friends did not have CF, Pete explained to him that there were other children who do:

*Well we told him that other children had the same thing with the sticky lungs and they had to have the capsules too with their food. "Oh, do other people have capsules with their food?" That was wonderful that he wasn't just the only one, that there were other people. Then he rushed off. We try and be as open about things as we can. We don't go into any gory details about any sort of stuff, and he wouldn't have a clue about life expectancy and all that sort of thing. He doesn't need to worry about that, cause you can't tell him an honest answer anyway. We worry about that enough for all of us. That's probably the worst thing, isn't it, not knowing.*

I wondered what they would tell Toby in response to that question, and when that will be in his process of discovery.

### **School**

When beginning school, the child with CF enters an arena in which the naivety and privacy that has been maintained within the family unit is now breached as gradual disclosure occurs at an unpredictable rate. It was a few days after Pete had "had his bit of a talk to him" that Toby had decided:

*I can't go to school today, cause you know what I've got. What if I go to school and make all the other kids sick? They won't be my friends anymore.*

Toby had processed the information and feared being relationally isolated from his friends, and potentially being responsible for harming them - not the usual group conforming tactics required for kindergarten, where issues of belonging do not usually extend beyond wearing a Bob the Builder T-shirt.

Kate continued:

*I said to him on the way to school: "If you get worried about it, you go and talk to Mrs. Lewis cause she knows and she'll be able to talk to you." And I worded her up*

*when I got there and that was fine, and then she said to me that he had come up to her during the day and said: "Do you know that I've got CF?" " Yes I do." " And you're still my friend?" And then up to one of his little friends and he said: "Do you know that I - ?" And she said: "Yes, my Mum told me." And he said: "Did you tell her Mum? Everybody knows. But they're all still my friends." So I think he was trying to re-establish his position in the world, that all of a sudden everybody knew that there was something wrong except him. Now he'd come to the understanding that there was something wrong, and he wanted to feel secure that everybody felt that he was just the same. And they didn't bat an eyelid. And he came home and he never mentioned it again.*

School is also a place geared towards children whose bodies perform more or less to an acceptable norm, their minds and behaviour being the prime targets in an educational milieu. Thus Kate and Pete, like other parents in this study, took on the task of teaching the teacher in a bid to alter the school culture to accommodate their child with CF. This was the result of their feeling that: "We weren't really making them realise," that teachers did not "really understand", because to their eye he looked "the same as anybody else." Hence Kate expressed:

*Like at school I found it really hard when he started up here this year. I had to try and draw the school's attention to the fact that you've got him from nine till three. I don't see him in that time. I can't look after him; you're going to have to do what I do. It was really, really difficult because obviously the capsules were one problem and going to the toilet was another problem.*

How were they going to entrust the care of their son's body to uninitiated others? Just as they had done for naïve medical experts, they became the facilitators of facts, having learned not to rely on, nor to wait for professionals in their world. Pete expounded:

*One thing we did do this year that was good. We sat down one weekend and we wrote a four-page thing on CF and we didn't pull any punches, and the staff invited us to attend their staff meeting. We sat round and basically gave them a half an hour*

*overview of CF and what's it all about and what's going on, and what his life is like on a daily basis.*

Kate “chipped in” as they talked to about 20 teachers who sat in silence and “never said a word. They just looked at us.” I concurred with the efficacy of them as parents being the messengers in this case:

*It comes home more personal too because you do it and you live it every day, than getting a sister from the hospital that doesn't live it every day, that sees kids in there when they're sick.*

I also appreciated the deathly silence, as Pete pulled no punches:

*You can't scare the living daylights out of them over something that mightn't happen, but you need to really slam it home to them that if you muck up his capsules, he's going to vomit six or seven times all over his bed, all over everything, and that is because you mucked his capsules up.*

Positive feedback came via a member of the unofficial parent network who Pete quoted as saying:

*They were just stunned with what you said. They've learned so much. They just had no idea of what you had to do on a daily basis and how his life will be.*

Their young son could now be supervised by teachers who were furnished with comprehensive instructions for care. For while there was no notion of a warranty agreement, compliance with best usage would mean a longer life, a goal towards which all others in their life world were required to aim.

School became a place where they could exert influence and achieve a therapeutic strategy comparable with home, and therefore an extension of it. This was unlike their institutional experience in the hospital, where care felt beyond their control, and elicited their declaration to stay out of there.

## No guarantees

It had taken Kate and Pete:

*Five and a half years to get that far. It's taken us a long time to sort of really realise and be comfortable with what we're doing, to be able to talk about it.*

Now they are proud. Boasted Pete:

*But at that clinic we were just real proud of him, like he just looked really well, and he'd been doing well, and we hadn't had any problems for months, and we said to the paediatrician: "What do you think? Look at this kid, he's a million bucks worth of kid here." And the doctor just sort of shook his head and said: "Oh yeah." I said: "Well what do you reckon? Are we going to talk where we're going here now?" And he said: "Well look I wouldn't guarantee he'd make it to ten." And we just fell off our chair, didn't we? We're sort of looking for 30 or 40 or 50 or something. And he said: "Oh well, next step is to get him to ten. I wouldn't guarantee it though." And we were devastated cause we think, well look at him. There's nothing wrong with him.*

They were in that window of opportunity through which parents of younger children with CF could look and see some years in which they could say: "He's not sick," even using the double negative as Brooke's mother had done. Yet beyond that horizon, clouds are certainly gathering, perhaps unseen at this stage, but yet perceived. Pete continued:

*We pull no punches. We have to accept that we're going to make the distance or maybe not, as far he's concerned, time-wise. But it's no good - I mean if something's going to happen to him, it's going to be over my dead body. But I'm also of the realisation that something could and there's not much I will be able to do about it. I mean we're doing everything we can and more, but if at the end, if you're number's up, well your number's up and there's nothing we can do; and you've got to understand that to keep on going with things. You've got to try and do your best. There's no good us putting our head in the sand and saying, Well it's not going to happen to us. Because that's just as likely to be the person it will happen to.*

Despite being tireless champions in the race for knowledge, self-made experts  
because of its absorption and dissemination, it represents but a finger in the dyke  
because:

*CF will surface and it will get you at some stage.*

## Toby talks

It is not easy to switch from stark statements of reality to chatting with the person who is their subject. Kate pre-empted:

*We said there's a lady coming today, and she's going to talk to him about CF. And he said: "I hope she doesn't want to know much Mum cause I don't know much about it." And I said: "You know about your physio and stuff like that." He said: "Oh yeah I could tell her about that, but I don't really know much about it."*

But he decided not to, preferring to express himself with felt pens and happy talking. He drew his family [overleaf] - no past or future sketch, but one situated in the now, for which time he included me in the people in his immediate world.

His parents appeared first on the paper, forming the anchor points around which to construct his world. That they were the same size and colour illustrated the uniformity of their presence and contribution in his life; which had been evident in their conversation with me.

Toby placed me as the central character in the family circle. Even though I was wearing green, he dressed me in bright red - his favourite colour - and depicted me as bigger than everyone else. This, combined with his chatter, conveyed his being comfortable with this person who had come to visit and to talk.

Whereas for the past hour his parents had discussed their lives with Toby as the central figure, he drew himself to one side, and childlike in size, linking himself to his parents by colouring himself the family blue. His yellow hair, a distinguishing feature, was in contrast with his parent's matching charcoal grey.

His statement of: "I catch a fish" was a delightful comment on the activity that they do together, one in which his parents can guarantee him success. As he talked on, I found myself hoping that he will catch many more fish, and that this family that "plays together" will indeed "stay together" for a very long time. I would not want to imagine a family sketch without him.

## Grace

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Sugar and spice  
And all things nice,  
That's what little girls are made of.

*Nursery rhyme*

From a little-boy-orientated house, where the path to the couch was paved with toy cars and trucks, my next interview was a total contrast. Amidst all things pink and fairy wings, four-year-old Grace and her two-year-old sister, Bronte, played happily while their parents, Brad and Cathy talked. They then invited Grace to join us and encouraged her to draw some pictures for me.

### Brad and Cathy

I was still in the realm of the recent diagnosis, that cataclysmic event having occurred but four years previously in little Grace's life. Pre-interview reflection had me considering this fact, and anticipating that, considering the age difference of seventeen years between her and Tim, what differences would I see? Surely there had been changes and innovations in terms of treatment and outcomes?

Despite Grace being diagnosed by the heel prick test that was not available to some of the earlier participants, there were several elements of these parents' tale that were reminiscent of those to whom I had spoken before. There were still the sessions of uncertainty with a child health nurse, wherein doubt was cast upon the new mother's adaptation and proficiency in her role, the proof being displayed by numbers on baby scales that quantify the body therein, and which fell well short of those projected in the normal growth chart posted above. Cathy explained:

*And she [the child health nurse] was weighing her and she was under weight, and she was saying if I was feeding her and how often I was feeding her, cause she was under weight.*

But while this professional and a parent stumbled in the darkness of naivety, there was an answer, a truth that someone else knew. Cathy went on:

*We didn't know why, and I think she rang my GP, and the GP said she wanted to talk to me. So then I got on the phone, and she said why Grace hasn't been putting on weight lately because she has CF, and I said: "What's that? I have no idea what that is." And she explained it to me, and I went out to Mum and just broke down, and burst out in tears, and then I rang Brad.*

I recalled Toby's parents' reporting that their child health nurse was relieved when finally their GP told them, because in that situation, other health professionals knew but the moment of divulgence rested with the medical practitioner.

In Cathy and Brad's case, their child health nurse was obviously unacquainted with this fact, and was left to fumble for answers until initiating a call to the one who knew. Such fascinating dynamics of the known and the unknown, those who know and those who do not. The path of CF would seem to be a sort of board game where one's movement is precipitated more by chance than by careful calculation, despite the intention of seeking out clues and designing a strategy of play that will ensure the maximum rounds of the board. It seems it is not always, however, to be a team game. Rather relationships with other players can be inequitable, with one player holding the card another requires, yet having neither knowledge of what to ask for or who holds it, the novice player is left to 'go fish.'

Now this was as Cathy explained, "a couple of weeks after the heel prick," a substantially reduced time compared with Tim, Bob and Hannah's parents, for example, all of whom endured over a devastating year with sickly children. Yet despite this relatively shorter time in which to build to a crescendo such as Toby's dad's: "What have we done?" and Bob's mother's: "Better if he'd died," Cathy and Brad similarly described their shock that their baby's poor weight gain was pathological not physiological. One you caused, one you did not, or more importantly, one you can fix, one you cannot.

Brad took up the narration, vividly recalling being on the end of the phone, hearing



his wife's distressed sobs at the other. No words because "I couldn't even talk really, I was crying that much." Brad relayed:

*It took a fair while to get it out of her what was wrong because she was a sobbing mess, and she didn't know what it was. I'd heard of it before but didn't know what it was. I knew it was serious but didn't know how serious. It was a shock.*

Whatever the decade, however, and whatever the length or brevity of the pre-diagnostic period, the finding of CF is not easily assimilated. Its precipitous entry is a shock because it is usually something unknown and for which one is unprepared. A measure of seriousness cannot initially be awarded within such a void, there being no criteria upon which to base it.

### **Information**

Brad's mentioning shock again emphasised its magnitude. Rather predictably, he proceeded to their resultant course of action:

*The initial finding out was the biggest shock cause we'd never heard of it. I mean we'd heard the name, but like I said, didn't know what it was. And then we had to find out everything we could, which scared us the more we found out.*

I noted that he described this as an active procedure using the first person plural, a process in which they were the instigators of information procurement. In the midst of a morass of information with neither guide nor interpreter to help them negotiate their way through, they were like those who find themselves in a foreign land they did not choose to visit, and, bereft of a source of direction, knowledge of the terrain or indeed, grasp of the language, are handed a hefty guide book that is written for inhabitants of that place. Their progression into the information forest only exacerbated their fear.

Cathy recalled:

*When we first went in there with her, they gave us all this information to read, reports, everything, a big thick book. So we had to sit down and study it, and I went*

*over it and over it and over it and over it. Oh it was just all from the hospital, they just gave us all these books.*

It seems they did not go over it just the once. Cathy's repetition of this delving demonstrated their desire to know as much as they could, plus the difficulty of understanding, and effort involved in attaining these facts. Or was there an element of repetitious reading in the hope that they may have missed one of the few positives - or that rereading lifespan projections may cause them to increase, or even reveal that one has misread it in the first place?

I tried to imagine their faces as they were handed this "big thick book." Not only are you new parents coping with an underweight baby, and the shock that she has a disease, but you must fit into your emotionally charged world the study of one large tome.

It would seem that this and accompanying works were not proffered in the context of a therapeutic relationship, coming rather from an institution - the hospital - the closest personalisation of the exchange being an anonymous "they."

While the parents of children such as Tim and Bob were info-dependent upon those professionals who were the holders of truth and distributors of printed materials, Cathy and Brad had the option of the Internet. Although a less regulated source, it was user friendly in not only accessibility, but also in the personalised sense of that expression. Brad explained:

*We've looked things up on the Internet before, in fact that might be a place of interest for you. We found quite a few different life stories on the Internet about people living with CF and whatnot. Quite a few on there that we've seen. Some of them are sad stories; some of them are good stories.*

Thus they not only gleaned facts, but also entered the life world of others with CF, and, in a sense, lost in the forest of fact, they felt they had met some guides.

These were people who did not initially need the truth graphically and in entirety,

unlike, perhaps, Toby's dad. They needed small doses, such as Brad described:

*Chemists have got little print out machines where you pick a topic and print out information about it. We've done that a couple of times. It's updated all the time.*

A flimsy pharmacy brochure is not only written in lay speak, but also emanates from a place that is friendly, familiar and normal.

### **Normal notions**

As did other parents for whom the child with CF was their first, Cathy and Brad considered Grace to be normal when there was want of a yardstick to disclose otherwise. Cathy reflected:

*It would be strange with her not having it really. Living with it has become normal, I mean we've known no difference, I mean she was our first child. A lot of people might see it as being hard or whatever, but we're sort of used to it. It's been there since the word go. It's not like it was our second child. We've just noticed how much easier it is with Bronte, who doesn't have it, luckily.*

When such a mirror comes along, normal is realigned. Until Bronte arrived, they had coped by the habituation, the getting used to, the readjusted way of life being a new normal - well, their version of it, anyway.

### **Just fine**

A desire to communicate notions of "normal" and "fine" infused these parents' narration. They were, I sensed, as keen to reassure themselves as they were me. Cathy described going to a CF clinic:

*Normally we're in and out because we don't really have any questions, because she's fine. We're in and out. We may take a little bit longer with the doctor, but we had to see the social worker about Grace going to school. So we had to get some forms to give to the school. If we didn't have to wait for that we would have been in and out of there within an hour, but it was over two hours we had to wait. The social worker was quite busy that day. But no, normally: "Have you any worries with bowels?"*

and I go: "No not really." "Okay then, she's fine."

At this point, Brad indulged in a retrospective consideration of their lives with CF thus far:

*So far, living with CF, for us at least, hasn't been too bad. There's been a lot of worry, but I suppose things could have been a lot worse. There's a lot of other things around that could be worse than CF. Like one of the blokes I work with, his daughter was born with, I forget the name of the condition, but basically she was born without any bones in her fingers.*

And like many of the parents I had interviewed before them, 'worse' needed to be clarified, to be painted in all its grim detail so that CF could lean towards the 'normal' and 'fine' ends of the trajectory for as long as possible. Because hospitalisation hovers.

#### **With a little bit of luck**

Brad was quick to tell me:

*I think we might be a little lucky. Apart from the medication that goes with the digestive system, we've only had to put her in hospital once with lung problems. Other than that we've been very lucky. As I understand, a lot of kids with CF are in and out of hospital all the time with lung problems. She's only had the one time. She was in hospital for a week.*

Cathy remembered the experience as "scary", but the scared one was not Grace:

*She was in hospital a week about eight months ago I suppose. It was scary. Like I was really scared for her. And I just didn't want to show it though, because if she picked it up in me. I mean she just picks up all that kind of stuff. I was trying to be calm. We went up there and I told her that she was going to sleep in a big bed and have her own little room. When we got in there, and she got on the bed and she started bouncing on the bed, and she was like happy.*

I was glad that they did have their own room, not just because of cross-infection issues, but so that this little girl could trust her mother's word and feel secure in this big place, because who knows when or how often she will need to visit in the future. But her daddy said:

*We just hope the lungs stay the way they are. She's had so little trouble with them so far. I think that's the biggest problem with CF is the lungs, so as long as that stays normal, she'll be right.*

Calling up that concept of normal yet again, Brad focused particularly on her lungs, which he depersonalised with the definite article, because the life of his little girl is dependent upon the smooth functioning of these pulmonary organs.

### **X-ray excess**

Hence the imperative of Grace's regular x-rays, a procedure that would see these devoted, caring, protective and sensitive parents administer an uncharacteristic force that was born of fear, and facilitated their fight to maintain these lungs. There was no option. Brad began:

*Before her recent, or it's not that recent, but her hospital visit, the x-rays, like she has x-rays every three or six months or something. Before her lung infection that she had, up until then, the doctors kept saying they were as clean as any other kid's lungs. She must have got some sort of infection at one stage and had to be put in hospital. Now they are as clear as a bell. I think he said the last x-ray was 95% better than when it was at it's worst. I'm sure she's due for another one again. She's really good taking her x-rays. The first three or four times, after she hit two, I suppose.*

That was a lot of traumatic sessions, I calculated. Cathy explained further:

*She'd lay on the bed, and because she was male-shy, and she still is, a male would come and take the x-ray, and she would see the male come along and put things on her, and these big things come on up here, and she would scream and there's no way. And like we had to really hold her down. It was so horrible, and she was screaming and we were holding her down.*

My mental picture at this point was indeed unpleasant, x-ray departments being the cold, bleak, metallic, frightening places they are. If one were asked to design a space that would create an ambience of apprehension, that would be it. As Cathy and Brad talked, I imagined the incident, the trauma of it all magnified by contemplating it from a child's view.

It certainly had an impact on Brad, who would:

*Never forget that time. I had to physically hold her to the bed, like force her to stay there. I'll tell you what she surprised me. I think she was two or three at the time. You've got no idea how much strength a little kid's got when they really don't want to be somewhere. Even the x-ray, you can see about that much of her head where she's got her mouth wide open. Oh, she was screaming her lungs out.*

How haunting the scream captured on film. Emotion and trauma exhumed and described, Brad now sealed it all in with:

*Don't like forcing her but there was no other way. She has to have it done.*

This statement represented a resolve that will see them cope not only with the inevitable future x-rays, but also their whole journey of living with CF.

Besides, they had, in this instance, found a solution, as Cathy described:

*Now when I take her, I always ask for a female cause she co-operates a lot more, and for the last year they've been letting her stand up, like her cuddling this board, and it's fine. Like if she has a female, it's nothing, she's really brave. Even when like, I've never had an x-ray, but just the thought of it, it would really scare me. But she goes in and out and happy, and she sees her bones, and she loves it. We tell her it's a photo of her bones. You have lots of photos of your bones, don't you Grace? It's a little hard to explain, you know, tell her to feel her arm, feel that hard bit inside, that's your bone, and feel it up here, and show them on the x-ray.*

Indeed it is a little hard to explain to a 4 year-old. Bones, lungs, enzymes - what is a child to think?

### **Smell the roses**

Cathy considered:

*She knows. I don't know if she understands but she knows she takes capsules because she's got cystic fibrosis. Bronte, I don't know if she understands, but she knows Grace has to take capsules because she's got CF, or sixty-five roses whatever it's called.*

'Sixty-five roses' is a phrase often used in relation to CF, adopted by some CF associations as a slogan. Anecdotally, it is said that a little boy, unable to pronounce the name of his sister's disease, told people she had 'sixty-five roses.' Such punning had occurred in this household, Cathy explaining:

*Bronte's actually said: "Three roses." I don't know where she got that from, but she said: "Grace has got three roses," and we just couldn't work it out. And Grace said: "She means I've got cystic fibrosis, Mummy!" I was shocked she could actually say it properly. Bronte knows that she doesn't take it because she doesn't have it. Grace takes it because she's got it. It's amazing that they can really understand.*

At this time, her understanding would seem to be limited to symptoms present and obvious, as opposed to those of future implication. As Cathy said:

*She knows it's got to do with - she coughs a lot, because she coughs a lot more than anyone else would. It gives her pains in the belly sometimes, and all that sort of thing. I think she's starting to understand.*

Because, after all, as Brad declared:

*It's just something she's got to live with. How do you know how a four-year-old mind works?*

How does one indeed?

Cathy continued the discussion:

*She's been taking her capsules since she was one month old so that's just normal to her. So if she didn't have to take them, it's just like: "Okay, where's my capsule?" She would miss it if she didn't have it.*

Once again, normal was the word of choice.

### **School days**

Affirmed in the family circle, how does the notion fare in the school setting - the place where 'normal' is still an important concept, but potentially problematic when you happen to have a different version? Brad told me:

*She's been going to preschool. She goes to kinder next but we would put a couple of capsules in her lunchbox. We told her and we told the teacher that she had to have them and she would do it by herself. She knew she had to take her capsules, so she'd fish them out and take them.*

For Grace, preschool was not a domain totally devoid of knowledge of CF:

*There was a lady who had a daughter - not going there - but she knew everything. But if she would ask me a question, I would tell her, but she seemed like she did know. She seemed to be pretty good with her. She would make sure she would take her enzymes before she ate anything, and she would just watch to make sure all the other kids - the other kids would help her find them, like poke around in the lunch - "Oh, there they are Grace, there they are." They would help her. I just didn't know how she'd go actually going there, and all the other children don't have to, but she does.*

Once again, enzymes in the lunchbox become an indicator. Fortunately Grace was well accepted. But Brad was realistic. It may not always be this way:

*I hope this doesn't make her stop taking them, or become a little bit more - It probably won't become an issue until half way through primary school, when things*



*like that might happen.*

Thus, while all had gone well that year, for Grace's beginning school proper the next, these parents were not going to chance it that someone would have insider knowledge. They would have to be active in the information dissemination process, sending it as a precursor and utilising the user-friendly format of the chemist brochure, as Brad relayed:

*It's updated all the time, and we got a printout of about three or four pages long about CF, and we just grabbed that and took it down to the school when we were enrolling Grace for kinder next year. It's just something for them to read so they knew what it was all about. Cause Grace's the first child they've had there with CF. They had no idea, so we had to find out all this information.*

The headmaster had a friend who had a child with CF. Added Cathy:

*The teachers that are going to be dealing with her had no idea at all. So we gave her everything we could think of, and the diet pyramid table, because when they do teach her that, they have to teach her a separate one to everyone else. They have to know that because if they teach her the normal one, she's going to think - they were quite interested to find out that her health pyramid, or whatever you call it, food table, her's is turned upside down.*

Seems like everything in their world is turned upside down - or back to front.

### **Taste and see**

Brad explained:

*Unlike any other person, they've got to watch what they eat and not to eat too much fat and eat healthy. Grace's a little bit back to front. She's got to have more fatty foods, like a so-called junk food diet is probably a little bit better for Grace because of the pancreas not producing the digestive enzymes properly, and the way the body absorbs whatever out of the foods. She needs to have more to compensate I suppose. She sweats a lot more salt than anyone else, so we've got to supplement her salt,*

*which means salt and vinegar chips and stuff, especially in summer when she's sweating, you've really got to watch her salt.*

Well-versed in the whys and wherefores of the CF diet, these parents were only too willing to supply Grace with junk food in the name of being therapeutic, a notion that always seems incongruous. One man's junk is another one's treasure, if it fosters the life of your four-year-old child.

Brad had worked out that:

*You notice just by kissing her on the forehead, if it's a hot day, you'll taste the salt on her lips. I think it's ten times more salt in the sweat.*

This observation reminded me that not only were this family several decades removed from treatment and survival forecasts as offered to Tim's and Bob's parents, but they were several centuries from the prognostic adage that would invest the aforementioned salty kiss with 'soon must die'. For now, as Brad mentioned, there is medication:

*And making sure she's getting enough medication when she eats. When you're giving her something you've got to think, okay how fatty is that - one, two, three? You just put a bit of a guess to it.*

### **In a nutshell**

How easy it all sounded, particularly in the present, with a child who is "fine" and for whom the CF experience was, as Brad summarised:

*I suppose, in a nutshell, it's medication; it's extra fatty foods, and salt supplement.*

But there was more.

### **A pat on the back**

"And patting on the back", added Cathy. There is always the incessant physiotherapy overlooked in Brad's statement, perhaps its mundaneness rendering it subliminal, as

in: 'How could I forget physio?', when it is probably one thing most families I talked with would like to erase from their minds and routines.

For Grace, Brad considered, physiotherapy is still fun, and can be incorporated into enjoyable activities:

*She's got a lot of blowing toys and stuff like that. I suppose this is fun for her. She got given it for a Christmas present. It's like a pipe really, but it's got like a basket on the end of it and it's got a little plastic ball. They blow it and the ball just rises on the air that you blow and then it falls back into the cap. It's quite good, good for her lungs.*

Grace's physiotherapy also included what Cathy called:

*Patting on the back. When she does get a little bit chunky in the throat, she's got to cough and we've got to pat, and all that sort of thing. To begin with, of course, we did everyday, because when she was born she was full of mucous, as you do as a baby. But nowadays it's only when she starts to come down with a cold or something. You can tell when she's getting funny in the chest because when she breathes it sort of clicks. So when that starts happening, we give her a bit of a pat on the back. Normally in the morning time you can tell, so I just do it straight after breakfast, and it's normal routine for Grace anyway. She's starting getting into the habit of coughing herself. You used to have to tell her all the time, because you could hear when her breathing was clicking or making a funny noise. You'd say: "Grace, do a cough", and she'd do a little one. So you'd say: "Cough bigger." But I've noticed - it's only been the last few weeks I've noticed her doing it herself. If she's got something, she'll do a big cough.*

In these last comments are the seeds of the process whereby children with CF gradually assumes the control and subsequent responsibility for both treatment regimes, and themselves. This course was described more consciously and fully by other parents in this study, who cited a desire to see their child independent in their living with CF. This is a noble and achievable goal until circumstances, such as Tim's immediately pre-transplant, deem them as dependent as they were when a very

young child, their illness trajectory meaning they have come a full cycle.

### **Not normal**

But for now, as Cathy said:

*As far as living with it now, it's just normal. Just making sure you give her her medication before she eats. If she starts to get a bit rattly in the chest, you give her a pat on the back. But other than that she's a normal four-year-old.*

Cathy needed to reiterate this notion of normal:

*When people ask or when we actually tell them, they look at you in shock because she just looks normal. When we say that and they say: "Oh she looks normal", well she is normal. She's a normal four-year-old, completely normal.*

Indeed Grace appeared ordinary. Had I just entered the room with no prior knowledge, I would firstly not have picked any of its occupants as being burdened with a disease; and secondly, if told that was the case, I would have not immediately been able to determine which child, based merely on criteria of looks and behaviour. The mantle of normal is divested, however, on occasions such as the one Cathy described:

*When people see her taking her capsules, they look at me really strangely. Like if we were out in town and she'd eat something, and like there's a whole group of people sitting around, you'd go: "Here Grace, take one," and they'll look, and if I catch them, they'll look at me and you know, they look away. They're probably thinking that I'm a bad mother and doing stuff. That's normal now. If people look at me strange, oh well. Their problem.*

But is she really so nonchalant? She continued:

*For Brad it's just, you know, that stuff doesn't bother him. For me it's: "What are people thinking of me?" Now I don't really care. They can think what they like. Normally you wouldn't give a child anything anyway, unless they've got something*

*where they have to take medication.*

And how, I wondered, is it for Grace, such early public appearances laying the foundation for her future coping behaviours in living with CF. Cathy told me:

*So long as Grace doesn't feel uncomfortable, and she doesn't. She's never felt uncomfortable taking them. Even, like, around other people she doesn't know, which is really good. It may be different when she's older, like, you know, a teenager, when she goes to high school and people start teasing her, which hopefully just doesn't happen. Which it shouldn't do. Then again you never know. Teenagers.*

Because in CF, you never know - where it came from and where it will end.

### **Family roots**

Cathy and Brad had no idea where CF came from in their family, Brad reporting:

*We don't know, but all we know is it's in the genes somewhere. It's come from somewhere. Unless we tested everyone in the family, we wouldn't know I suppose.*

Cathy added:

*I suppose it doesn't really matter where it's come from. She's got it. There's nothing - you can't change it, so it doesn't really matter where it comes from.*

The news of Grace's having CF shocked their family. Was their reaction just in sympathy with Brad and Cathy, and their child's plight? Or was it because they were not only relationally tied to them, but also genetically, and, like some whodunit that has not yet been solved, one of them was the unrevealed carrier? Said Brad:

*Everyone was upset. I don't think many of the family knew what it was. I suppose the only one would have been my aunt because she was a nurse. She knew what it was, but most people didn't know. So it was a shock to everyone.*

"A big shock," Cathy concurred.

So shock waves had rippled out beyond that opening scenario of these two and their baby; and had now evolved into waves of fear, of uncertainty, as the future contemplated was a future unknown.

#### **A future far-off**

Cathy speculated:

*I reckon we'll get through it. I suppose it's a long way away yet though. Hopefully.*

These sentiments were reminiscent of Bob's "long way to go yet." Brad dug a little deeper into his surmising:

*The worst of it was the initial finding out, but living with it for us really hasn't been too bad. It's just part of life now. Of course we still worry about what the future holds, as every parent worries about the future, as far as your kids are concerned. Probably a little bit more so with Grace. We don't know how or if it's going to get worse, or stay the same, or get better.*

For him, the future, CF itself, is "just a big question mark really."

## Grace's grasp

If I were John  
And he were me  
Then He'd be six  
And I'd be three.

If John were me  
And I were John,  
I shouldn't have these trousers on.

- A A Milne, *Now We are Six*

The two little girls had played busily as their parents had talked. Earlier, Brad had encouraged Grace to tell me about her CF, but she did not want to talk about that, not with someone you have only just met that day. Far better to tell that someone something more relevant, more important. Thus as Grace now joined in the conversation, she was very keen to establish with me not only her age, but also, that in relation to Bronte, she was the elder. She filled me in:

*Bronte's two and a little bit. I'm four and Bronte's two. I'm going to be five next and Bronte's going to be three next. And I'm going to have another birthday.*

I asked her about kindergarten that year, to which she replied:

*I'm going to that big school when I'm bigger.*

Grace then chose to draw a self-portrait [overleaf], omitting her body, presenting just a smiling face. She proceeded to painstakingly craft her name above it, this detail being subsequently removed from her drawing to maintain her anonymity. At my response of: "My goodness you're very clever," she quickly retorted: "Yes." Cathy joined back in:

*She really wanted to write, so we'd do her name and get her to copy it. And she got so frustrated. She wanted to do it and she couldn't do it. She put her head down and that was it.*

"I did it!" Grace had cried, as she completed the final letter of her name. I somehow

think there are going to be many more such challenges into which she will need to set that head resolutely. When the novelty of open slather junk food has worn off, and others who kiss you will not want you to taste like a packet of crisps, she will need such determination.



## Mark

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Such attractions as are by no means unusual - children of two or three years old; an imperfect articulation, an earnest desire of having his [sic] own way, many cunning tricks, and a great deal of noise ...

- Jane Austen, *Sense and Sensibility*

Two-year-old Mark's mother, Dianne, suggested late morning would be a suitable time for me to call - rest time for Mark and his one year old brother Alex. So with the occasional little face appearing around the door, Dianne talked freely about their life thus far. Following an initial invitation, she was not stuck for words. Inferring that he leaves 'such things' to his wife, Mark's father, Philip, had declined to participate. Mark, likewise, did not contribute formally as his spoken language was insufficient, as were his drawing capabilities. Watching he and his brother enjoying lunch was, however, enlightening, as they leapt excitedly about, with Mark competently swallowing his enzymes without batting an eyelid.

## Dianne

### Definitive diagnosis

Dianne's opening words were: "We found out when he was four weeks old," certainly a more definite statement than other parents had thus far uttered. This, coupled with her next statement, suggested that this would be quite a different testimony from that of others. She continued on:

*They found out on the heel prick test. I had to volunteer him for the heel prick test because it wasn't on his notes.*

These words conveyed that from the start, this mother was on guard and watching, aware of discrepancy and omission.

*The nurse came in and said: "Would you like to volunteer your child for a heel prick test?" And I said: "Yes, why not?"*

While there was ambiguity in Dianne's rendition of this scenario, her volunteering being in response to the nurse's invitation, her perception was that the onus had rested with her. She was the one who had to be alert in a system she was unable to trust, against which she was subconsciously building a case.

And what was her response to the nurse's query? - "Why not?"

Why not, indeed. And just as well, because from this test invested with the adjectives 'just' and 'routine', which lull participants into a sleepy state of 'won't happen to us', the positive result precipitated an awakening that Dianne described as "devastating," particularly when she had done all the right things in the neonatal period:

*Because I didn't smoke when I was pregnant with him, and it took the doctor - not that I'll mention the doctor's name - two and a half hours to say that it looks like he's got it. He might have it. He's got it. He might have it. Two and a half hours, yes, for the doctor to tell me that. And I walked out of the hospital and I was like shaking.*

The professional others were meant to support the main characters, Dianne and baby Mark enacting the birth process that was meant to be uneventful. Now these people were assuming roles that she had not anticipated, that had not figured in her imagined script, and they were delivering their lines devoid of the style, method and speed that she would have preferred. Whatever the doctor had said, to Dianne it was confusing and ambiguous, and occupied a time span well beyond that of her concentration. It would seem that the doctor did not comprehend the particular needs of this mother at this time, and in attempting to ease the diagnosis divulgence, had obviously allowed plenty of time for her to hear and explore the news. But sadly, it was a misconnection because Dianne concluded:

*It would have been all right if she had got straight to the point and said, look he's got it. Plain and simple, but she didn't.*

There would seem to be no pat way, no neat recipe of: 'How to tell a family they have CF,' because each brings to the interchange an understanding of vocabulary, and a communication style that may not interlink with the other. Hence the difficulty of

trying to decipher at what level to pitch words which do not slide in easily at any. I recalled Toby's father's observation that, in similar circumstances, he felt the doctor was "talking over our heads", a dynamic perhaps equally the result of the listeners being "shell-shocked" as much as not having a clue about that which was being discussed.

Thus the doctor in this case may have continued for two and a half hours in an attempt to explain. Was it in fact that long? Or, for Dianne, did this overwhelming news slip her from the present into some elongated timeframe that was not exactly eternal, but had that inescapable feeling of forever.

This was a mother who did not 'beat about the bush':

*That doctor whom I hate, and I've been told many other people don't like - if she had got straight to the point, I probably wouldn't have taken smoking back up again.*

Blame was being apportioned, and a case continued to be mounted. This is perhaps the only recourse for those who are confronting a disease they have never heard of before, and are left with the quandary of "where did it come from?"

Dianne's first reported action after the news was: "I walked out of the hospital," as Tim's mother had recalled doing two decades earlier. It was a manoeuvre both women calculatedly placed in their narrative, being of chronological and geographical significance. They did not jump from diagnosis to 'when I got home', for example. Rather they both have strong recollections of exiting the hospital into which they had entered as the mother of a perfect baby boy, and left it with a tarnished image of what that child would become. They were spilled out the self-opening doors into a life that was inexorably altered. A place that had echoed with the joyous news of: "It's a boy," had equally resounded with the news that life conferred would be life deferred, and to that institution they would be back.

### **United we stand**

Her dialogue appeared to be that of one negotiating alone, but Dianne added:

*No. I had Philip with me. Anything concerned with Mark now, with the CF, we do it together. Because Philip's workmate understands it if we've got to take Mark to the doctor, I ring Philip and he comes home. Straight home. No question. Because as Philip said, he'd rather quit than let his family down.*

This couple were a united front against the foe of CF, and as I was to understand, against those others - be they medical or social support - who, while having responsibility for Marks' welfare, did not fulfil this in the manner that these parents required. Dianne added a footnote:

*No. Like these sort of things he doesn't really like. He leaves them to me. He says: "You talk to them."*

Recalling our first meeting at the clinic, I was aware that Dianne was the spokesperson for this family, and that there was an assumption that only she would be present for this interview.

We proceeded on with "this sort of thing" to chat about life with this disease that they had never heard of before, but about which they needed to learn.

### **We regret to inform you**

Dianne colourfully recalled the sincerely proffered foundational information they received:

*One of the doctors said that Philip and I have got two genes each, and we've also got the CF gene, and blah, blah, blah, blah. It was all blah, blah, blah.*

Did the speaker realise that this was their interpretation of the talk? What information did these parents require in that moment; or does being in a state of shock mean that after the initial condemning sentence is uttered, any words do not compute? It would seem that Dianne and Philip were furnished with an abundance of fact, while others such as Brooke's mother, felt that information was either scarce or obsolete.

## Antisocial

Dianne and Philip were not only overwhelmed with new medical language, that of disease, treatment and genetics, but also with all these new others in their world. Their world had been framed by a rustic cottage in a tiny country town half an hour's drive - and a lifetime - away from this land of giants. But these parents would not quietly retire to their rural retreat. They would fight; and they would start with the social worker:

*The thing I really didn't like was that they, no sooner did they find out, but they shove the social worker onto us. And here I am, all upset just finding out that my newborn baby has got CF and they're shoving this complete stranger onto me. Talk about it!*

By no means an amicable, therapeutic relationship with another, the perception of this conversation is of a "shoving" and "onto", descriptors of an action perceived both as forceful and landing upon. This interaction ended with the resolve:

*And I told her where to go. I have to admit it was hard to start with, but you have to do it, plain and simple. You have to do it.*

But they took the social worker's pamphlets:

*I did some reading on it, read all the pamphlets and that, and it didn't take all that long.*

Then, as in the game of Chinese Whispers, these two who grappled to understand the information:

*Had to explain it to everybody we knew, like my mother.*

I wondered how it filtered out to them. Said Dianne:

*She used to be a trained nurse and I told her, and she turned around and said: "Oh, is that from the formula you've been feeding him?" I said: "No Mum, it's genetic."*

It would seem from her reply that Dianne had accumulated more information than she realised:

*I just had to explain it to everybody, so it just rolls out of my head now. They turn around and say, what is CF? And I just say it's systemic and lung disease, and that the mucus that goes through everybody's body, in Mark is thicker, and he can't get his enzymes to digest his food.*

Like the other parents I had interviewed, Dianne and Philip had taken on the fact finding mission with a vengeance, speaking it with a lingo that would no doubt 'amaze your family and impress your friends', because, as Dianne continued:

*My eldest brother had a little girl and I told him: "You make sure she gets a heel prick test." I said: "You make sure." I said: "If I'm a carrier, there's a chance that you'll be a carrier too." I haven't heard anything back from that so I hope she hasn't got it.*

They may not, however, appreciate the significance of her cajoling, because she may have erroneously told them, as she did me, that:

*There's a one in a million chances of two CF parents getting together and having kids.*

But for those who had never heard of it just a few years before, they were not doing too badly in the absorption, assimilation and dissemination of information.

### **School days**

This sharing of knowledge extended to the school Mark would be attending when he was old enough for kindergarten:

*I told the school up here, when he starts - I went up there and I did the Red Roses theme one term.*

She had utilised the official CF emblem cum fundraising symbol to orientate the school to this disease that her son would be bringing with him when he came. It seems, however, that her exhortation did not end there:

*Yes, and I told them straight. I said: "If my boy comes home crying because he's been teased about taking his enzymes," I said, "I'm taking him out." They said: "You can't do that." I said: "You watch me." I said: "I prefer to drive him to another school so he won't be teased." I know that's probably going overboard but I won't have it. I'd rather, coming down to the nitty gritty, I'd rather take him home than take him to school. I'm not going to let him have that added pressure.*

In Mark's world, others will not be permitted to add to his disease burden - not if his mother has anything to do with it. Others will need to come into line, and to participate at a level she will deem acceptable. How else is a mother to protect her little boy against a disease that cannot be controlled? But people and circumstances, at least, can be. Other parents had undertaken the education of the school community as a process of disseminating facts in their attempts to make it a safe space for their child. Dianne had delivered her knowledge tainted with the threats of one for whom, perhaps, a more articulate presentation had eluded.

Philip wanted Mark to begin kindergarten when he was four, but Dianne had told him:

*I said; "No, five. He's starting when he's five." At least at five he's old enough. I mean he knows now, but he's old enough to realise that he's got to take his medicine. Like he's old enough now, but he'll be more confident with it at five years old.*

Then he would be more able to negotiate the enzyme and lunchbox routine that, by virtue of participant repetition, is somewhat of a rite of passage for these little people with CF.

At this stage, Dianne believed that Mark did not "think he's different." Rather he just:

*Knows that he's got to take his medicine. He will not eat his dinner unless he has his medicine. He knows he's got to have it. If he complains, we tell him that if you don't*

*have it, then you get sick and end up in hospital. I turn around and say: "You don't like hospital, do you?" And he says: "No!" So I say: "Take your medicine."*

No positive reinforcement or encouragement such as: 'You'll grow up to be big and strong like daddy,' or introductory highlighting of his body, its particular needs, and the benefits of looking after it. Rather, Dianne used the hospital as a threat. I wondered what sort of association with that institution she was setting up for the future. It is a place to which he will need to be willing go, and in which he will have to trust the people who care for him. Because, despite taking your medicine, there have already been times when this has not kept the scourge at bay, such as his one and only - so far - hospital admission.

### **Hospital hallways**

Dianne remembered it well:

*He's been on borderline pneumonia. That's when he spent a couple of days in hospital. We'd been told that if he ever went to hospital, he would get his own room. It didn't happen. I was furious. I didn't know who to talk to about it. I was just so furious.*

In this unfamiliar place, Dianne was unable to decipher who it was that she should speak to about her concerns. Who should - or could - she approach? How was she to relate in this unfamiliar milieu?

*I went out for a smoke, and an orderly asked me what was wrong. I told him, and he said: "He should have his own room." And I said: "I know that; you know that." And their excuse was that there wasn't any single rooms left, but there was, because when we first arrived, I counted up three spare rooms, single rooms.*

But she had found an ally, an alternative source of medical information emphatically given in agreement with her. Did those who should have heard her request know that she had such misgivings? These were well-supported ones, because this vigilant one who had been watching since Mark's birth, had done her own reconnaissance, counting what appeared to be available rooms. She continued:



*He had the ward to himself to start with. Later that night, a little boy came up and he had a virus that made it look like he had appendicitis. And the day after that, another little boy came up with pneumonia in the same room.*

As she spoke, I noticed that same frustration that Hannah's father had conveyed when talking about hospital. With a sense of futility, both knew that despite their protestations, if such are not couched in appropriate wording or manner, they may be overlooked by those who communicate that they know best. Hence her telling them:

*"I hope you know I'm going to be sleeping next to his bed?" If Mark ever has to go to hospital again, I'll continue going with him until he was old enough to tell me not to. Until he was old enough to tell me, look Mummy I don't need you. You can go home now.*

I noted that she said "if" in connection with any future hospitalisations for Mark. As one who had spoken at length to other parents in this study, I mentally substituted "when." But she and Philip may have different expectations of the disease of which they have been presented with a revised version.

Whatever eventuates, however, one thing seems sure - in hospital or out - she will stand her ground. She will not leave her post. She will fight.

### **A bloody mess**

What had been the reason for Mark's one - and only - admission? Dianne was keen to tell me:

*Because he threw blood up, in town. That was quite scary that was. We were in town and he was grizzling. I thought he was just upset because of sitting in the pram. I looked back and found blood clots up the boy. And I mean blood clots everywhere, and I thought, shit. So I rang Philip and I said get up to the hospital, I'll be there in a minute.*

While she had deemed this unforeseen incident as "scary", Dianne considered,

*I wasn't frightened. I was just concerned for Mark. Mind you he had his good outfit on. So I took him up to Myer, cleaned him up, found a taxi that took me up to the hospital. Went up there and they couldn't figure out why he threw blood up. They did a chest x-ray and saw that he was on borderline pneumonia, so it was a blessing in disguise. He spent three days in hospital and on the Friday night, he was sweating like a little pig, and they couldn't tell me why, couldn't tell me why. Like, I know CF kids sweat. I know that, but he'd never sweated that much. And they still couldn't tell me why he threw blood up for.*

Concern gave way to frustration by the third night:

*I was so frustrated Friday night. I went and sat in the corridor and bawled my eyes out. Not that I was sad, I was just angry and upset that they couldn't tell me why he'd brung that up for and why he was sweating.*

She had found the safe place of the corridor, reminiscent of Bob's mother, who could remember sitting in a corridor, crying. It is a space where, firstly, the child for whom you have had to appear strong, will not witness your distress. Secondly, it is a place where you feel you can actually release a torrent, and you do not have to interact, this time, with those whose mandate it is to walk with you through these confusing times - whether you want them to or not.

Dianne's frustration seemed compounded by a lack of communication, not so much that "they couldn't tell me," but possibly because, like Hannah's father, she was not *au fait* with the language nor with the contextual competency required to build a rapport with medical staff.

She was spotted in that corridor, but this time it was okay. She was not delivered a serving of facts, the caring words not including her son this time:

*The nurse came up to me and said: "If you had a car, you wouldn't be here, would you?" And I said: "No!"*

Someone had connected with her, had seen through the fighter at the bedside, and by speaking as they did, acknowledged that Dianne's will to fight was equally balanced with a desire for flight.

### **Over there**

Now flight was not always in response to fright or difficult circumstances. For Dianne it also held a more literal connotation, as I was to hear. In the description of mixing with others with CF, she said:

*No, keep to ourselves. Just go to CF clinic, that's it. If there's a major, major meeting about CF, yes, we'd probably go, but only the CF clinic. I like the combined one, because the Melbourne group over, so in case anything majorly happens to Mark and he's got to go over there, that they are his mates.*

So while the local hospital is used as a threat, the bigger one "over there" is invested with the camaraderie of "mates", whom you need when "over there" is a place you have never been. But for this woman, who had never been out of her island state, the idea of going was not such a negative one:

*That's why I was so excited when they said I had to go over to Melbourne. I thought, oh crikey, I get to have an aeroplane ride!*

But this did not eventuate, and so she had still not flown - yet:

*Even an aeroplane ride from here to Hobart would have made me happy.*

Certainly more exciting than a taxi ride from town.

### **Legal action**

In another way, this was a mother determined to get somewhere by way of compensation from those she believed had caused a grievance:

*After we had the sweat test done, I got in contact with - it took another week or two to get the results back from that. An old friend of mine, a lawyer friend, he said I would*

*have had a good case if he hadn't had it. I said what for? He said I could've sued the hospital for undue stress and undue grief, and I would have had a good case.*

Is this the new breed of parents whose child has CF, I wondered, considering Toby's parents contemplation of similar action? How far removed from the parents of the older children in this study, who would have welcomed an available test, a two-week wait for a definite diagnosis appearing rapid when compared with the months of trauma through which they had struggled. But maybe stress and grief born of uncertainty are not quantifiable in units of time, the only recourse to relieve those who are hurting being to get back at the ones who initiated their hurt:

*When the sweat test came in, Dr. Martin rang me up and said: "He's got it." I said: "Are you sure?" And he said: "Yes." And I said: "Bugger" And he said: "Why?" And I said: "Oh I was hoping to sue you." He just laughed. But I would have, if he didn't have it.*

That avenue closed, she turned her attention to other agencies:

*I just don't think it's fair. Like, with Centrelink at the moment, I've got a battle going on with them. When Mark was four weeks old, we went for the Carer's Allowance for him, and got a letter back from them saying he wasn't up to the level. I was not very happy about that at all. So I got on the phone and I said: "What do you mean my bloody son's not up to the level?" And they said: "It's all got to do with numbers." So I said: "Stuff your damn numbers." So I hung up and didn't do anything for then. And we went for it the other week and he's minus three and is supposed to be minus zero to get it.*

Paucity of numbers was not heralded by these parents as a positive expression of Mark's disease status and of their effective care. Rather it was a numerical representation of how far they were from the financial entitlement they sought. Time to enlist the aid of those who could speak on their behalf:

*The lawyer told me that all Centrelink needs is a letter from Mark's doctor, saying he's either got to have antibiotics, physio or enzymes every day. And he's got to have*

*physio and that, every day. So I got one from his GP, and I got one from Dr. Martin, and my lawyer sent a lovely little letter along with it. I told him to send me a copy, so I could keep it in my records, and it's a lovely little letter. He wanted to know why everybody else in the State was getting the allowance for children with CF, but the local office was different. And I got a letter back from Centrelink saying that they're going to review it. I haven't heard back from them.*

These parents are working hard. Angry at not having their efforts acknowledged nor rewarded, Dianne considered:

*The forms for the Carer's Allowance have got nothing on it about CF. Like the only reason he is the way he is, is because we look after him. I said to the lady, I said: "What, does he have to go on a bloody respirator before he gets it?" No, it's got to do with numbers or something like that. I was fuming. I'm willing to fight it. I don't care how far I've got to go. It's not fair.*

I wanted to tell her to conserve that energy and courage for dealing with CF, and that strength for the daily relentless treatment of symptoms that, as they progress, will appear grossly unfair indeed.

Not only is fight motivated by a sense of injustice, but also the fact that an extra dollar or two would not go astray.

### **Cost analysis**

As reported by other parents in this study, the daily cost of CF is calculated not only in emotional and physical terms, but a financial investment is also required. Said Dianne:

*Do you know it's cost more to put Mark into childcare than any other kid because of his CF? Philip rang up about four childcare centres, and for a normal child it would be about \$50 for the day, but for Mark \$70, \$80.*

This is the price extracted for children who require:

*Special care. And Philip turned around and said he would prefer to take time off work. That's a day's pay.*

But all in all, she concluded that the monetary burden was not excessive:

*Apart from dipping into my pension every now and then to get stuff for him. I can live with that. Putting all the bits of the nebuliser together I figure that was about \$75. I can live with that. Just his enzymes and his vitamin supplement and that's it. Only antibiotics if he gets sick.*

I noted how routine was her mention of vitamins, as mundane as his enzymes. When Mark was born, Toby's parents were contemplating confessing their illicit vitamin use to their doctor. Meanwhile Brooke's parents were being recommended something that they had been giving their daughter all along.

### **Family and friends**

Cost also extends to relationships, those with family and friends needing work, and vigilance to stand up for their little boy in the fight to present and establish him as normal. By way of a summation, Dianne relayed:

*They ask how Mark is going. They've learned not to ask how Mark is going with his CF, because I hate it. I loathe it. From anybody. They come up to me and say: "How's Mark going with his CF?" And I hate it that people put the disease before him. Mark is before the disease in my eye. So I say: "Mark is doing fine." As I said, it's a disease, but it's not more important than Mark. Mark is more important than the disease. If people can't fix that up in their mind, there's something wrong with them.*

I wondered if the concerned enquirers did not, in fact, do so, would they then be berated for not caring or being uninterested in the disease that has impacted this family's life? It seems it is appropriate for them to ask, but it needs to be sufficiently removed in the conversation to represent the distance that Philip and Dianne fight to maintain between him and the disease about which family and friends may not be very aware - as they had been but a year or two ago. Ten minutes is the quantity of

time that Dianne feels is an acceptable demarcation between Mark and CF. Any closer together:

*I just hate it. If ever I hear it - ohhh. It makes me cringe. I feel like going, arrgh! Then they wait for ten minutes and ask how Mark is going with his CF. That's fine. I can cope with that. They've asked how Mark is first. My father-in-law does it every now and then. He says: "Oh, how's he going with his CF?" And I say: "Fine" through gritted teeth. That's what gets on my nerves, is people just, you know, put the disease before the person. I don't like it, but they're learning.*

I silently admired her goal of not identifying the child by his disease, an objective more easily achieved by those who understand it.

### **Not contagious**

For all the bravado that Dianne had conveyed, I sensed that it masked a sensitivity and vulnerability for these parents who had not had too many years to build up to a level such as Grace's parents had, wherein they could say they did not care what people thought. Dianne was still processing encounters such as this:

*And then there's one of our ex-friends. He was holding Mark and we'd just found out, and we told him, and he handed him back. I was holding him and I said: "What did you do that for"? And he said: "Do what?" I said: "You passed him back to me." And he turned around and said: "Oh did I?" I said: "Yes, you did. He's not contagious or anything. You won't catch it."*

It would seem that the offender did so without being aware that handing the baby back was an offensive act. When the child is invested with a disease label, it is. Did the friend's action display disinterest, and confirm what she was starting to realise about CF?:

*I've got nothing against cancer or leukaemia or anything, but you see all this fund-raising for cancer and leukaemia and that, but you don't see much about CF, and that really gets me going. It gets me going. I think to myself, it's not fair. What's the difference between them? I know that people die of cancer and leukaemia at probably*

*an early age, but people die of CF too. So what's the difference between them? They're both life-threatening diseases. So why can't they show more interest in different diseases?*

Because, although you do not want CF spoken too close to your child's name, there is the inevitability of the knowledge that it will not go away.

### **Kick along**

"It's always there," Dianne told me. She reflected further upon her philosophy of such matters:

*So, oh well, that's life. Got to be strong with it.*

She was quick to add: "Can't change it," this finality leading to a consideration of a future thus prescribed. Not surprisingly, she said she did:

*Think about the future, but the future will take care of itself. I'll think about that when it gets here. That's what I'll do. I'll think about the future when it gets here. Yes, a day at a time. That's all I can do. Because Mark could die tomorrow. You just never know.*

All their fighting, educating and just plain telling will realise no guarantees. For Mark, there is always the possibility that tomorrow may not come. Dianne was uncharacteristically nonchalant on this matter:

*If it happens, it happens. The way I see things, anything with CF or anything, it was meant to be. You can't change it. It was meant to be. If you can change it, it wasn't supposed to be. But if you can't, that's it. You live with it. Kick along with it, as my friend says.*

This resignation belied the woman who had enlisted the help of lawyers and taken on the establishment. But these mere mortals were a prospect for change. CF, however, was not. Best to save that strength and determination for those things that are not.



### **Lunch break**

At this point there were noises off, and little faces took turns at peeking around the bedroom door, surveying the scene that included someone who was not there when they had gone for their nap. Shyness kept them at a distance for many minutes, hunger then bringing them closer to the kitchen and to lunch. Not having much language at his disposal, Mark decided that I needed to view each of his toy cars, which were silently offered to me for my perusal in a welcoming gesture. This interchange was interrupted by Dianne's food preparations, and Mark's realisation that it was enzymes time, because that was obviously how the routine was around there. With no hesitation, he swallowed the capsules without any consideration or self-consciousness that I was watching. For, at this phase of his life, at least, home is the *inner sanctum* wherein CF is mundane and treatment just something you do.

## On reflection

How subjective is this research process. After each interview, without exception I reflected that I am the richer as a result of the encounter. My research resolve enhanced, I determined to write about the participants' experience, making available to those who care for these young ones and their parents the understandings I have gained.

The potential therapeutic effect for participants in qualitative research has not been adequately explored (Koch1998:1186). Talking about their life world gives them the opportunity to order their experience. I considered this as a beneficial exercise in itself:

*Each time it impacts me anew - that people do welcome an opportunity to be heard - to unburden the years of living, to allow me into the inner sanctum of their family circle in order to catch a glimpse of their very private, personal struggles and pains. It's as if they say: "We're on this journey, won't you ride along with us for a bit? We'll tell you about the rest of our travels so far, we'll revive the moments, describe the scenery, reminisce the experience - and weep afresh. Please, share it with us. Oh, yes, for all the grand notions of research altruism - but really it's for us - we too have benefited from being the viewer of our lives, as we cast a retrospective glance over years that have shaped and moulded us, and made us, for better or worse, the anonymous participants who inhabit the world of the pseudonym, safe in the knowledge that you have renamed us. If only it was that easy to be distanced from our experience and the trauma to come. But no, we are the self-confessed 'better-for-it' ones - thank you for coming" (Jessup 2003 unpublished journal).*

## Gathering it all together

Thus were the interviews completed, and the data collected. By no means a finished process, it has taken on its own dynamic momentum, as I have sought to present as faithful an account as finite words can do. The progression continues, as the data becomes the subject of further discussion.

## A periscopic perspective: data discussed

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All cases are unique, and some are very similar to others.

-T.S.Eliot, *The Cocktail Party*

Challenged by the question of my practice colleagues, I have set out to explore the experience of living with CF. As my original scanning of the current literature left my queries unanswered, I consulted the experts - those whose narratives have been the data and subject of the preceding analysis chapter, wherein I have viewed their experience through the filters of time, body, space and relationship (van Manen 1990:101). Now, by further consideration, the phenomenon of living with CF will become apparent, and the subject of the ensuing discussion.

### Foliate themes

As I have delved into the data, distinct sub-themes have become apparent. I have designated them 'foliate' - leaf-like themes - a concept in harmony with the arboreal analogy used to describe phenomenology. Foliate stands equally as a verb, meaning to split into laminae - layers, a process that has emerged through the research process.

I recognised these dynamics as being heightened and distinct on the part of the narrators, and yet connected when assembled under this researcher's eye. That they all began with a phonic tone of 'f' added further cohesion to these themes. Recurring throughout the participant's accounts, they are rather like themes of a different kind - signature tunes hummed by the phenomenon that no longer eluded, but was coming into focus.

It is now appropriate to consider those recurrences of fright, fear, fight, flight, familiarity, form, future and philosophy. Discussion of these elements will facilitate consideration of the phenomenon under investigation.

## Fright

While fright and fear were enunciated separately in the participants' narratives, they were not discrete entities. Rather, fright - 'sudden fear or violent terror' (Concise Oxford Dictionary 1979:423) - was, to utilise medical terminology, an acute, initial episode, whereas fear - 'painful emotion caused by impending danger or evil' (p.380) - lingered as chronically as CF itself.

Episodes of fright punctuated participant's tales, usually beginning with the biggest fright of all, diagnosis - a surreal, devastating time. Bob's mother correlated her experience with being shipwrecked, feeling "all at sea", Swiss Family Robinson style:

The tempest had lasted six days, and far from abating, now redoubled in fury. Driven out of our course to the south-west, it was impossible to tell in what parts we were. Our vessel had lost her masts, and leaked from end to end.

(Johann Wyss 1781-1830 )

Initial tumult abated, families found themselves washed up in parts unknown, cut off from the mundane and familiar, and needing to find their bearings and reconstruct their lives in the context of a new, unanticipated scenario. 'Cystic' and 'fibrosis' were merely words some parents may have heard of. Others confronted them for the first time in the same sentence with their child's name, once uttered, never forgotten.

For Bob and Ian's parents, the precipitating event had been the acute incident of meconium ileus that alerted them within days of their baby's birth that all was not perfect. For others, it was a pronouncement after traumatic weeks or months of coping with a sickly child displaying an array of symptoms that health professionals either verbally minimised, or did not equate with a disease entity. The problem was often designated to be that of the parents - notably the distraught mother. Diagnosis is a term derived from the Greek *gignosko* (Concise Oxford Dictionary 1979:284), meaning to recognise, implying the phenomenon already exists, but is camouflaged in anonymity born of non-acquaintance or, as in the case of several medical carers, the mis-reading of the sign posts.

While Grace and Mark's parents had the benefit of the heel prick test, the former still endured several weeks of self-castigation regarding their parenting prowess. Although

participants described a diversity of happenings preceding diagnosis, this did not alter the fact that it represented the driving of a grotesque stake into the foundation of their lives, behind which was life as known, and beyond which was life revised. It was inevitable that parents started their stories at this juncture. Where else indeed would they begin?

A fright is so because victims have neither warning nor inkling that their lifeworld trajectory is to be suddenly intercepted with a phenomenon that until then may not have existed in their realm. A corollary to fright is shock, a state that is exhibited across the emotional and corporeal planes, requiring physical release. The descriptions of tears formed a steady stream throughout the 20 years of diagnoses about which I have heard. Some wept in anguish, while for other participants, like Dianne, the knee-jerk reaction was one of anger.

I recalled those parents I had read about in the literature, depicted as those who have had a fright, and are in a state of resultant shock (Moore 1988:10). The fact of CF being an unknown placed it in bogeyman class. What is it? How frightful is it? Details such as these, parents were often left to procure for themselves. As has been seen in this project, answers to these questions were shielded by medical carers who sometimes played such cards close to their chest. How reminiscent of the description of a 'conspiracy of silence' (p. 10), in which mothers sensed the seriousness of their child's condition from unspoken clues such as the countenance of colluding staff.

For the parents in my study, fright at diagnosis was as tangible and overwhelming for more recently diagnosed cases, such as Grace's and Mark's, as it had been for Tim's two decades before. CF being totally unknown to any of them meant that, initially anyway, knowledge of the latest prognostic predictions and cure regimes offered neither alleviation nor stemming of the flow of tears. Initial facts actually exacerbated their fears, as a stark reality was depicted, described by Cathy as "scaring us the more we found out."

The heel prick test substantially reduced the time until diagnosis, permitting some parents to quote waiting periods in days or weeks. They would be unaware, and probably incredulous of, the debate that continues regarding the efficacy of mass

screening versus the extra financial cost it requires (Kunk 1998:266). While diagnosis is a shock, it has been documented that the knowledge that at least it has been made early, renders relief that prophylactic treatment has been instigated as soon as possible to minimise damage of an irreversible kind (Dodge 1998b:411).

That their fright was subsequent to a quagmire of indeterminate symptoms or inaccurate initial diagnosis did not lessen its impact even when compared with those for whom there were no such signs and symptoms. This fright never fully abated, settling instead as a cloud of fear that hovered like a backdrop to the daily enactment of their lives.

Discussion so far has centred on parents because the disease all began with them, diagnosis being also a form of telling of their genetic fortune, in which the future is reconceptualized not only because of the care their child with CF will incur, but also the implications for future offspring. Would these parents have wanted to know these facts before they reproduced, before they formed the relationship that besides being a heady emotion was a mathematical calculation regarding odds (Polnay et al. 2002: 284)? Would such calculus have affected their relational chemistry?

But before leaving the discussion of fright, I was conscious that fright had not only occurred to parents. Scares occurred later in the chronology of those who actually have the disease. They disclosed frights that for them were like a stark moment of the actual reality of having CF, a disease that, via a significant fright, went from being a bother to potentially life threatening after all. Their watersheds included sudden episodes of haemoptysis, friends dying within earshot and eyeshot, or equally traumatic false alarms when, at 21, your first potential call for lung transplant is a wrong number. Initial diagnosis fright has lessened. Never fully abating, it has been the precursor of pervasive, subliminal fear that is never far below the cognisant level.

## **Fear**

C.S. Lewis (1961) writes: "No one ever told me that grief felt so like fear." This dynamic is ongoing. As these children and their parents conveyed their life

experience, it has been infused with a subtext of loitering death, and attended by a fear of, and grieving for, both present and impending loss. Liz nominated diagnosis a “shock”, precipitating her “having to learn to deal with the grief” as fright settled into an insidious, ongoing fear.

I had considered it a cloud that daily cast a shadow. Fear now appeared more intrinsic than that. Is it the foundation on which their lives are shakily constructed? Conversely, is it a case that from the initial stake driven into their experience, subsequent posts continue to be driven, forming a fence line, a boundary inside which is contained life, daily painstaking routines and treatment, and relationships? And parents are left pondering, as Toby’s did: “What sort of life are we going to have?”

### **Fear of failure**

The child’s life is now a quantified one, situated on a continuum of facts and figures, against which efforts of both child and primarily, their parents, are assessed for immediate efficiency, and ultimately for a pass/fail finality (Melnik et al. 2001:548-558). Thus they are dogged by a fear of failure, of not being successful in their ministrations of a medical regime for which they had never bargained when opting for parenthood. Ultimately to be unsuccessful is a *fait accompli*. No matter how rigorous the practice, nor how efficiently the young person with CF assumes responsibility for it, it remains tainted by, as Pete bemoaned, the knowledge that: “CF will surface and it will get you at some stage.” Subtext: we will fail. He will die. Where will it be in the run of numbers that do not figure in the childhoods of children not so encumbered? A day will come when the counting ceases. A line is drawn to rule off the account. Life is finally measured and no longer quantified.

After eight years of living with CF, Brooke knew enough to fear potential, or inevitable, excruciating scenarios of disease progression and its management. Hence the fast forward facility in her idealistic remote controlled life, safer by far than the fearful unknown about which she had an inkling.

Grace would have appreciated such an option as she was first held, terrified, on the torturous x-ray table. Her subsequent ongoing fear was permanently captured freeze-frame.

### **Friend or foe**

How naïve two-year-old Mark now seemed, the one for whom fear was apportioned to strangers such as me, the unknown lady who came to his house, and other strangers who did frightening things when he had his hospital sojourn. For the older children, such fears had gradually dispelled, as foes became friends who Hannah, for example, recalled fondly by name. That which is initially feared, can ultimately become an ally when dangers of vaster proportions present. How is a child to know that they are so? What is their baseline for comparison? I suspect that well before numbers were assigned significance when calculated with height, lung function or potential lifespan, there would have been an hereditary interchange of a more subtle kind, when each of those frightened mothers and subsequently, fathers, looked anew at their baby, with fear inscribed in eyes that could never view them with carefree delight again. Because, despite parents' efforts to hide it, they are the ones who convey this difference to their child, like Bob's "I think I always knew it," or Tim's "I knew I was different straightaway."

Hence Tim's relief on his 15<sup>th</sup> birthday, the marker that had been bandied about as his quota in the original forecast, and a milestone his parents were not aware he was fearfully looking out for. How unlike other young people, for whom birthdays are preceded by 'when' not 'if', and are attended with a sense of accruing years, not depleting a limited, undesignated supply.

Relief for his stepfather was written on his face, at seeing Tim emerge from the bedroom that may have become his tomb, Stuart's confessed fear of Tim dying always being in the background. Fear of the silence of death was theory for this man, but not so for his stepson and at least one other young adult in this study.

### **Scared to death**

Both Tim and Bob had heard the death throes, the resuscitation clamour, the trolley carrying the armoury of life being raced noisily to a bedside, but then silently wheeled away when fear had culminated, and been experienced finally, for one person with CF. Of what it consists for the one in the next room - in the next bed - an onlooker can merely conjecture. For Tim, it had been a fright that had meant a recalculation of his fear, that of having a lung transplant now being outweighed by his not.



Coping with bereavement is not a regular phase in adolescents' lives, write Rask et al. (2002:137). The experience precipitates a fear of their own potentially premature death, a sensation that hinders their coping with their associated grief. Fear is magnified markedly when you and the deceased have not only friendship but also diagnosis in common.

It seems inevitable for the CF life to cease with a fight, the final response to fear. A dynamic that has infused and perpetuated the existence of both the child with CF and their parents, fear elicits a response and enlists them for life.

## **Fight**

Thus is engendered the concept of fight. Whereas parents have been described in the literature as being in an initial state of denial (Coyne 1997:123), those in this study have not overtly conveyed this. Following diagnosis, parents were not explicitly told to fight. They did not have to be coached. It was a strategic stance adopted not only in response to fear, but also in alleviation of a sense of powerlessness and a lack of control that can overwhelm the life of those dealt a hand they did not elect to play. For the participants in this study, fight was verbally expressed: *against* CF - in a daily rigorous regime of incessant physiotherapy and medication; *for* the child - a parent can no longer be passive - for example, school has to be educated; and *for* information. Those with CF have been nurtured within such a climate, and involved in a process of gradually assuming their own role in what is essentially the fight for life. It is waged in the public arena - school, legal - and in the private domain - to achieve normal life, length of life, and to comply with the treatment routine.

## **Outside orientation**

Where other parents might be passive participants in a schooling programme, those whose child has CF have to assume a difference stance - they have to fight for their child. So, for example, school has to be educated. Not in the usual role of an institution from which to glean instruction and knowledge, it is one in which must be sown an understanding of CF that will result in the school community becoming an ally in fighting. Anything less is just not an option, as conveyed by Julie, and, should

Dianne's local school not come up to standard, she will simply not leave her son there. Thus school can be a safe place, therapeutically sound and an extension of home. It is into such an arena that parents then feel confident to place their child, albeit moderated by their continual assessment. Nothing is ever settled or finished. No days off.

School is an arena into which the children go alone, and here begins their fight for acceptance, to grasp the normative criteria that are the password into membership of a group that on the one hand proffers peer support, but on the other, must be assessed for suitability for disclosure (Admi 1995:489).

Accounts convey that for these children, living a life with CF means that there is always extra energy expended to strategise, to stay afloat, to stay alive. The uncomplicated habit of enzyme taking, for example, has featured without exception in participants' dialogue. A skill learned and applauded *en famille*, with a first public performance often in restaurants, albeit still in the company of committed parents, is now subject to scrutiny. The child with CF is now negotiating how the procedure can be subsumed both visually and time wise to permit keeping in step with the school group, whose initial view is likewise one of curious onlookers. As opposed to casual café diners, however, they need to be ingratiated as friends, and enlisted in the fight.

Mark and Grace were yet to confront this challenge. Toby was just realising that not everyone does physiotherapy, while Brooke was busily reconstructing the enzyme enigma to fit into a world in which lunch carries the connotation of nutrition rather than therapy - a subtle difference she had recently observed for herself.

While parents' fight may be focused in the classroom, for their children it continues in the playground. Parents can attempt to exert influence upon the professional care of their child, but the interrelationship of peers is one negotiation in which they cannot, by virtue of definition, participate.

Older children in the study still conveyed school scenarios tainted with fight. Hannah conceded defeat at the beginning of high school, when her struggle with an exacerbation of acquired illnesses resulted in her current home schooling programme.

Her conveyed sense of relief led me to believe that daily isolation from pathogenic organisms was equally attended by not needing to commence school initiation anew.

Bob, by contrast, had enjoyed the liberty of his early schooling years at home, unencumbered by the fight for acceptance. Thus in his description of his subsequent transfer to boarding school, he portrayed himself as isolated within the crowd into which he did not initially realise he had to fight his way. Ian's fight had not only been to procure schoolyard acceptance, but also classroom approval. It was at his mother's direction that he stood up to the teacher who seemed locked in conflict with him.

### **Legal ligature**

Out of frustration some parents contemplated fight in the legal arena. Pete retrospectively considered that his lawyer "would just make mince-meat out of" the doctor who supplied initial erroneous information regarding CF. Mark's pugnacious mother was engaged in fisticuffs with a government welfare agency, a spar fortified by letters from her lawyer. Dianne had decided not to take on the local hospital. Such reaction and recourse is afforded those children and parents living with CF in this current litigious climate. No such mutterings emanated from those parents of the 1980's children, for whom medical and government institutions represented both security and hope; and whose authoritative word, not to be considered erroneous, was final. Besides, the fight against the disease extracted energy enough.

### **'Neb, meds, puffers, physio and enzymes ...'**

The fight against CF is not a Monday to Friday one, with weekends off. It demands that the attacker be continually vigilant. 'Neb, meds, puffers, physio and enzymes' - the CF chant - describes the routine that is undertaken daily, habitually, continually - and any other word that will convey no time off, no unguarded moment. Some parents could label it "routine now", a statement that depicts their having painted CF into the background of their daily activities - for now. In other households, however, therapy was traumatic, demanding coercion, such as Tim's description of his parents playing board games to anchor him long enough for nebulisers. Clare vividly recalled fighting against her baby son in her attempts to percuss his tiny chest, her wrestle being not only against him, but also with her nurturing emotions that threatened to initiate her retreat.

These parents' and children's fight has not always been congruous. While Hannah's dad was fighting for the flourishing of her body, she appeared determined to prevent its growth. Meanwhile, his combat with the system seemed more akin to guerrilla warfare, while Hannah was adept at, and enjoying, negotiating within it. Social worker - friend or foe?

Subtle is the fight as child attempts to separate from parents, a normative process complicated by the latter's disease investment. It would see Hannah confessing annoyance at her dad's suggestion of what to wear, or Tim assessing his relationship with his mother as "love/ hate" - in direct contrast with the latter's perception of it as "very close."

### **Quest for information**

As I listened to the parents' narratives, there was a pervading reference to the fight for information, particularly in the initial diagnostic phase. I had imagined that in the current climate of diverse media, appropriate information would be given. However, some parents felt overwhelmed by copious detail, such as Dianne, who translated what she perceived as "blah, blah, blah", what is heard being quite different from what is said (Moore 1988:10). By contrast, Nigel and Clare had studied genetics and so had the lingo, at least. They felt deprived of details, the obtaining of which was akin to "getting blood from a stone." Liz deduced that there was information specific to nurses and doctors, and she read all she could, "not just the stuff they want the parents to hear." This was just as well, because this enabled her to recognise the flawed facts she was given.

None of the parents reported an appropriate delivery or quantity of information. That they all conveyed dissatisfaction may have been moderated not so much by mode and amount, but that it consisted of facts that they would rather not have heard, and which possibly no amount of garnishing could have rendered palatable.

It would seem that the dose and timing of administration of these specifics is predetermined by medical professionals according to a standard proforma, rather than being individually tailored within the context of a therapeutic relationship.

Toby's parents felt as though their informants were "talking over our heads", not necessarily because of a lack of correct language, but because they were "shell-shocked". Were those imparting the knowledge aware that this was the case? Kate and Pete had enough insight to recognise that "when did he catch it?" was not a valid question. It was, instead, typical of outdated and erroneous fact, which almost humorous in naivety, only served to erode any trust that the beginner parents in this study had accrued. But it did alert them to another fact - that this was yet another arena in which they would have to fight, not only to get the latest facts, but also to be part of the circle within which these facts are readily disseminated.

The fight, however, is for more than just enlightening facts. Information delivery is documented in the literature as actually being perceived as part of social support (Puotiniemi et al. 2001:299), its acquisition conferring partnership between the parents and the professional in their child's care. Equally informed means equal standing, with no doubt a sense of empowerment on the part of the parents, who have to attain a standard of expertise of medical care to undertake the everyday fight with CF.

Parents have 'an overwhelming desire for information regarding their child's condition and treatment' (Fisher 2001:604). While some in this study were furnished with pamphlets, others with substantial books, and still others delivered a verbal rundown, all were engaged in a fight driven by the reality that the world they knew had ended (p.601). Information on the new world is essential to know of what it consists, and how they are to build a new life within it, one that will have to resemble as close to normal as they can manage, albeit a revised version thereof.

Hence Pete's plea for "centralised care for someone getting the right treatment, the right advice." Inherent in his vision would have been the homogeneity of information from a composite centre that could service both those with CF and professional alike. Because, it seems, there are glaring discrepancies in the scenarios that were conveyed by various medical carers quoted throughout this study. Are those professional possessors of fact aware that their understanding may have reflected experience with the last child with CF they have attended in a former era of circumstances? Are they now enlightened to the current status of prognosis and treatment? Might a quest for

current information be pertinent for them also, particularly regarding a disease like CF, where understanding and compliance are essential to the maintenance of life (Hinton et al. 2002:18)?

Nigel offered his summation of the information dilemma: "Most people felt they were told too much. And here we were thinking we weren't told enough. So we were actually not necessarily the average person that they're trying to plan their procedure around." Having heard the variety of experiences told to me, it would seem that 'average' is not applicable to the world of living with a chronic, life-threatening illness.

### **Children's talk**

While parents had fought for information, their children were the beneficiaries of their efforts. Parents are charged with the task of disseminating it to their child. In the context of this relationship, information is filtered, and then couched in the vernacular that befits each child, by the adults who know them best. However, Grace's glib pronunciation of the "sixty-five roses" slogan was not only a surprise to Cathy, but also an indicator that information is gleaned informally by attuned young eyes and ears.

Several weeks before I visited Toby, he had had a moment of realisation when viewing television during CF Week, and saw other children with "the sticky lungs" who "had to have the capsules too." He was aware that his knowledge was incomplete. As far as sharing information with me, he had earlier told his mother: "I hope she doesn't want to know much Mum, cause I don't know much about it." She had reminded him of his insider acquaintance with physiotherapy, about which he decided he could tell, albeit he did not "really know much about it" - compared with what he perceived an adult might wish to hear. He obviously decided to leave information of the advanced kind to those who take care of those things for now, choosing instead to draw - a task to which he felt much more suited as the child in this interchange. At this stage, he was in no way motivated to fight to apprehend any further details.

Although wrestling with information has been an overarching issue for their parents, it has not featured in the accounts of the adolescents and young adults in this project. A study into materials such as videos and books available for those with CF suggests that children's informational needs may differ from their parents, and while children are the specific focus of some resources, they are rarely consulted in the provision thereof (Hinton et al. 2002:18). Such material may not be as vital for them, however, given that their parents have fought on their behalf to procure the facts. Plus, as with most issues about which they wonder, the World Wide Web is a main area of inquiry for young Internet surfers, and a means whereby their horizons widen.

### **A normal battle**

A hunger for information is linked to parents' desire and fight for normality (Fisher 2001:605). Studies of those whose children have a variety of chronic illnesses - diabetes and rheumatoid arthritis - have found that over time, parents come to view both the child and their life as normal (Knafl & Deatrick 2002:49). Normal is relative, appraised according to the extent of the assessor's experience. Several mothers in this project realised that it was not until they had a subsequent child without CF that the contrast of caring for the second child prompted a reconsideration of their understanding with the first, rewriting those memories as not usual. Grace's mother had reflected:

*It would be strange her not having it really. Living with it has become normal. I mean we've known no difference. She was our first child. A lot of people might see it as hard, but we're sort of used to it. It's been there since the word go ... We've just noticed how much easier it is with Bronte, who doesn't have it, luckily."*

At this stage of Grace's life with CF, Cathy stated categorically: "She is normal. She's a normal four-year-old, completely normal."

By no means an 'either-or' situation, parents describe varying degrees of normalisation, and recognise that it is not always attainable (Knafl & Deatrick 2002:53). Liz was able to state, however, that, as far as CF went, her family have been "lucky", and able to "put it in and have a normal life on top of it," differentiating between her 'normal' and that perceived by someone else. Who is to say whose is the

valid rendition? Is it a case of not either-or, but rather a continuum along which daily life is enacted? Bluebond-Langer (1996) depicts those living with CF as attempting to preserve a semblance of normal life by actually redefining normal, plus reassessing priorities and reconceptualizing the future. According to Liz, CF is foundational - something that is inserted and upon which a façade of 'normal' shakily constructed. This is an effective strategy when your child is relatively well, but not so when, for example, like Tim, activities of daily living elude the domain of the usual.

A child's fight for normal is more monumental, and is waged in arenas beyond that of home and parental control. It is confronted in schoolyard and classroom alike, a battle focused in prosaic receptacles such as a lunchbox, a container for the enzymes with which no one else in that context is encumbered. It is a criterion for activity involvement, such as school camps, when more novel apparatus like a nebuliser could wreck your disguise and divulge your position. It is ultimately waged in the mind, wherein risk is assessed, devious methods of camouflaging equipment conceived, and calculating the minimal use thereof required for maintenance calculated. An added conception is the image of body and behaviours that is a mental fusion of yours with that which all your friends perceive as normal.

### **Final round**

Life with CF is a fight to the finish, one in which parents are engaged whatever the cost, emotionally and financially, being conscripts into the role of caregiver. While other parents have occasion to fight for their child, for most it is not a life and death struggle. "An uphill battle" is how Pete describes theirs. The nature of that battle is typified by Dianne's admonition that she would be "willing to fight it. I don't care how far I've got to go." To the very end, it seems.

For the child with CF, there are no before and after images. The atmosphere of fight is one that is as intrinsic to their life as CF itself, and, as they become increasingly aware, a battle in which they are signed up for life, however long that may be.



## Flight

Fright and fight have often led to flight. Invariably, participants have included integral flight in their account somewhere, with attendant concepts of 'here/there', 'over there', going *to* Melbourne; the people *from* Melbourne, one parent contemplating flying to Disneyland while they still could.

Most are descriptions of actual trips taken. Others are reactionary, and represent the search for possibilities that may exist elsewhere, or the metaphorical notion of flights of fancy - ascendancy above a condition from which, paradoxically, there is actually no escape.

## Flight to

Flight is not a surprising consideration, given the island state in which the participants live. Their lifeworlds are consequently moderated by a pervading sense of isolation and rurality. Feeling cut off geographically from an expansive mainland is reflected in their narratives. They consider they are excluded from "over there", a world wherein, they perceive, big is not only better, but also the epicentre of where the latest, the best and, hopefully, the cure, are to be found.

Hence their consistent reference to "the ones from Melbourne", who are like a lifeline to those who feel somewhat cast adrift and are looking out for a light on the horizon. Such a sentiment may be exacerbated by the perception, as expressed by Pete, that there is "no centralised care", "those from Melbourne" delivering a metered biannual dose of the consolation these parents crave. These visitors from the outside world offer security plus cohesiveness because, as Liz assessed: "They are definitely a lot more informed, because they are in paediatrics for one particular area." And besides, on sheer weight of numbers, she deduced: "Over there, there's a lot more CF."

Relocating to larger centres was mooted in most parents' scenarios, and actually executed in some, such as Bob's island hopping. When Toby's family moved, their larger centre was an intrastate one, which others had not only designated small but from which they had sought escape. It was, however, a drawcard for Kate and Pete, away from a service they had experienced as inept. Having moved, their horizon was

extended, as they joined those peering across the watery divide over which all had considered shifting.

Liz discussed plans to “go over to Melbourne for her updates.” Ross had contemplated a move to warmer climes, both for Hannah’s benefit and to propel his family out of a rut. His being berated for seeking the benefit of sun and surf appeared to have not only quashed his plans, but also fuelled his resentment against those authorities who held the controlling strings of his, and Hannah’s, day to day existence. The main thrust of the rebuke seemed to be the fact that Ross was seeking benefit for himself in this supposed flight of fancy. With my enhanced understanding of parents coping with CF, I wonder, would that have been so bad?

Several children and their parents had flights for short-term relocations “over there”, airlifted into another world. For some, it proved to be a wilderness experience, as for Ann, who felt disorientated. She described her flight home from Melbourne on one occasion as reminiscent of a precipitous re-entry in which there was no time to readjust to her usual altitude of existence.

For their offspring with CF, it was flight to an oasis. When Ian was at a particularly low point emotionally, Julie encouraged him to “go over there”, an expedition from which he came back “a new kid,” a secondary spin off being his establishing rapport with “the ones over there.” For Tim, a departure “over there” had been a trip to pick up his new lungs - the ultimate flight of a lifetime.

### **Flight from**

Flight has been articulated in other parents’ accounts - flight from perceived erroneous information and improper care, particularly when measured against reliable outside sources. This was typified for Toby’s parents by: “When did he catch it?” Likewise, Liz contemplated flight from the ignorance of medical carers, including the physiotherapist who considered “it was unusual it was a girl”, and the nurse who was emphatic that: “No, they can’t do any sport.” Professionals with a correct supply of fact do not feature in the discussion. Is their legitimate dialogue drowned out by the magnification which misinformation seems to attain? Has such a rational voice even been heard?

There is more subtle flight - from the truth, couched in expressions like Liz's "she's fine." Is this an escape from the inevitable, or a concerted bid to be anywhere but here?

### **Flight through life**

Behind all the discussion is Brooke chatting about her remote, pointing out its main features and alluding to a place other than here and now, the flight to which can bypass those unmentionables of outcome and care. While other participants have not overtly indicated a desire to be translated to an easier scenario, their flight through life has certainly taken on a momentum of its own, being one in which they will have to pack in as much living as possible. Toby is unaware that this could even include dashes to Disneyland, which his parents had originally considered when diagnosis precipitated them into the express lane of existence, albeit fuelled by an erroneous prediction. I suspect most would not elect to fast forward over the difficult bits, as they would not want to cut down what is already an edited version, desiring rather a pause in the action to catch a breath.

For Mark, flight had been limited to trips to town, and a mercy dash to the local hospital by taxi. Dianne bemoaned the fact that she is still waiting for "an aeroplane ride". Those further along in this unique life with CF could no doubt tell her that it is no joy ride.

### **Is it a bird? Is it a plane?**

Ian took his first flight when only two-days old. Tim's most recent one was when two days may have been his last. Other children's experience falls intermittently in between, in a succession of flight that for those without CF would have represented holiday or an adventure of some kind. For those living with this chronic, life-threatening disease, ascension above the clouds is geographical, by aviation means, and concomitantly abstract wherein ascendancy is attempted by a planned escape from the personal isolation of those who perceive no hope, yet yearn to fly free.

## Familiarity

The concept of family as parents had planned is irretrievably altered. No longer an intimate circle of relationship in which offspring are reared, it now includes various medical carers, some “here” and those from “over there.” It also strives, and expends inordinate energy, to retrieve a semblance of normal, when the notion that one of its members is not so, and will be prematurely deleted from the group. Uncertainty flows over into other relationships, tainting those with extended family and friends.

Ann attributed having a sick child to the break-up of her first marriage, contributed to by blame and dispute over the sharing of Tim’s treatment and care. There has been a propensity to assess relationship strain between the parents of a child with chronic illness using divorce statistics, such a finite outcome not accounting for those interactions wherein tension is palpable but partners do not separate (Eiser 1993:138), or those partnerships where there has been no legal contractual agreement.

A Canadian study (Solomon & Breton 1999:236) concludes that while results show that having a child with CF ‘did not appear to affect marital relations negatively’, their participants ‘may have been suppressing problems at the time’. Regarding their relationship with their child, such parents laughed less than a control group, and were more directive, serious and less encouraging when interacting with them. I considered these results difficult to correlate with the interactions I had enjoyed with the participants in my project, and with their narratives. While they had disclosed unique tensions and difficulties, their interaction with both me and their child was infused with a capacity that went well beyond ‘putting on a brave face.’ This thought is, however, tempered by my understanding that there would have been *entre nous* moments, when stark reality and laborious routine synergise.

Some parents in this study have negotiated an amenable contribution to the daily routine. Garry had cut his workdays to enable Liz to conduct her business. Interaction for these people included walks and bike rides, and the annoying dog, which Brooke delightedly thought “got in the way”.

Kate and Pete discussed their conclusion of recreational togetherness because “how can you have a wonderful sporting career” when “your child’s sitting at home” and your spouse has to “look after him?” On reflection, they could tell me that four was the number of times they had been out together, without their son, since his birth five years before. They also drew on the philosophy that the “family that plays together stays together”. This may have come about from necessity but now had resulted in warm interaction between parents and child, an outcome influenced as much by inevitability as by the subconscious knowledge that ‘there’s always next year’ is not a certainty.

Thus it would have been difficult for Nigel and Clare to select the boarding school option, and to sacrifice daily relationship in Bob’s adolescent years for potential educational benefit in a future that is by no means guaranteed. Leaving their farm and moving to be with him when he was not flourishing in his school environment was, on the one hand, a difficult upheaval and loss, but on the other, situated Bob back into the relational context from which he derived security and affirmation. I also sensed relief on the part of his parents, who had been parted perhaps once too often from this young man.

### **Poles apart**

There is a tendency to depict life with CF in a negative hue, both in the literature and in the reactions of onlookers. Canda (2001:121), however, himself a CF sufferer, correlates awareness of mortality with heightened quality of relationships and appreciation for life. McDonough (1998:6) highlights the personal difficulty those with CF can encounter when ‘CF is perceived only as a tragedy, rather than an opportunity or a process of discovery.’ Tim quipped that he is unable to die yet “because I’ve got a set of things now that I want to do”, his progression through life subject to a personal mandate rather than a tragic actualisation.

Parents are reportedly able to find positive attributes of their child’s illness and its impact on their lives (Katz 2002:453). “It’s probably made me a stronger person ... the one I am today”, considered Ann, while Stuart spoke affectionately of his sons, including the two little boys who, as Tim describes, “just love me to death”. Stuart’s declaration: “That’s our family” extolled a bond that clearly has been strengthened by

late night dashes to planes; juggling care, work and picking up children; and simply seeing Tim emerge in the morning, still alive for another day, a dynamic that, I have noticed, increases in value - in the eye of the beholder, anyway.

In his drawing, Toby had depicted his parents with a uniformity of size and colour, perhaps his perception of them and their relationship both to each other and to their contribution in his life with CF. How do they view him and this disease? It has been documented (Katz 2002:454) that mothers and fathers tend to have differing perceptions of their child's life-threatening chronic illness. I considered this in light of the parents with whom I had spoken. For Kate and Pete, and indeed each situation in which I interviewed both parents, there would seem to have been a consensus in their appreciation of the gravity of the disease, and in their commitment to the care of their child, to the prolongation of their lifespan, with an attendant desire for quality, not just quantity of years. There is, however, a flipside to Toby's duplication of his parents. His lack of differentiation graphically illustrates the reduced sense of individual freedom, as Pete acquiesced: "You tend to lose your individuality with it."

Those occasions when I spoke with one parent, their partner was portrayed as comprehending the CF reality and being motivated in its alleviation. As Dianne emphasised: "Anything concerned with CF, we do it together." If required during the day, Philip "comes straight home". Liz praised her husband as being "actually really good ... We do everything pretty much half and half." Although these are, in a sense, one-eyed accounts, there appears to be no differing perception of impact of CF between the parents in this project, the mutual support derived from their relationships being only too evident.

For those parents who had thus successfully negotiated treatment roles, solidarity was obvious. Equally apparent was a depth of relationship that is perhaps denied those who do not have to candidly discourse on the life and death issues that a child with CF faces. As Ann relayed her experience in her son's early years, she described the jostling within the therapy regime, a struggle in which no one really won. She lost her first husband's support and affection, and Tim lost the daily presence of the father who may not have been as aware of the gravity of the disease and consequent therapy imperative. Thus CF brought a divide between father and son, one that was

reinforced further when Brian's subsequent wife could not accommodate a treatment schedule towards which she would not have been emotionally motivated. Paternal closeness was subsequently fostered in a Royal Flying Doctor plane at night, and in a big city "over there."

Characteristically, mothers are the main ones to interact with professionals (Katz 2002:455), and hence the assumption with several parents that these women would be the spokesperson for that partnership when it came to my visit. As Nigel confessed: "It's familiar territory of course, but mums remember all the gory details."

No such option was accorded Hannah's father, who had no mutual support in the interactions with his daughter's carers that he found so trying. Lask (2003:42) punctuates the CF experience with 'physical, emotional, social and practical burdens' that stretch coping mechanisms to the limit. Resultant client/clinician conflict in the form of disagreement, misunderstanding and impaired trust is magnified, particularly when any interchange is viewed through the perspective of one pair of eyes.

So the parents in this study are by no means an homogenous set, but are among the myriad of those who have child a with CF, with their own unique interpretation and response to illness (Coyne 1997:126). They are people whose participation in the process of procreation did not render a gentle initiation into the role of parenthood. Rather it meant they had to swiftly become assessors of odds, expert treatment clinicians, and technicians. They were required to establish rapport on an equal footing with medical staff whose role they would have once considered intermittent for physiological matters, but was now concurrent and for issues pathological. I was impressed with not only how accomplished these parents had become, but how much of the ordinary they were able to project. But this is also a façade that they are used to presenting, and one behind which they seemed relieved to allow me to look.

It is also an edifice that they have not built up alone, but one in which others have aided in the construction, by their reaction to the CF dilemma. Extended family were in some instances supportive, but in others did not want to know. In some cases, such as Mark's, they literally "passed the baby back" when told. I recalled Clare's plaintive recollection that "nobody wanted to touch him ...maybe one brave person."

Kate and Pete portrayed supposedly close family as not wanting to baby-sit, while Julie vividly recalled her mother-in-law's words: "How can you bring another child into the world with that?" While I initially considered these reactions with disdain, I wonder whether declining to hold these children or be responsible for their welfare was the result of feeling inadequate that they would not be able to do it right, or as well as, these proficient parents, especially when even the words you said were not acceptable? Did enquirers about Mark realise they should ask about the boy first then his disease, with a suitable time lapse between the two? Was Ian and Max's grandmother's exclamation out of concern for her son and daughter-in-law, who appeared encumbered enough already with CF?

Cathy and Liz had rallied support from their mothers, within the context of that maternal relationship. It was, however, as Ann discussed the results of carrier status testing of this once-removed generation, that I considered the possibility of their guilt for being a carrier on the one hand, or relief at not having it, on the other, yet feeling guilty about that (Emery 2001:82). Parents of the child with CF could not understand the resultant relational distancing, and felt overwhelmed by it.

Within the extended family, disclosure of CF and its repercussions is not always mandatory, but is inevitable. It was after diagnosis that Julie raised the topic of CF with her aunt in Melbourne, who was then obliged to disclose her own son's disease.

In the contemporary climate of genetic testing carrying an implied 'social responsibility' and the subtle ridding the family of deleterious genes (Hallowell 1999:597), the parents with whom I talked were modifying their family's gene pool by their particular decisions of disclosure and further pregnancies. They considered these choices as private business, input such as Ian's grandmother's outburst being regarded intrusive. Some extended family members had elected to be genetically assayed, the process being infused with an air of voluntary election - for adult carrier status at least. For children of extended family, the heel prick test was more than a response to a nurse's invitation, as Dianne had reported. Her insistence that her niece be tested would have been an obligatory procedure because of Mark's diagnosis, but thus was also a frightening one. It could prove to be too much, and hence the



distancing from the parents and their child with CF, as occurred in several participants' accounts.

### **Seen and heard**

The children in this study chatted, drew and wrote about CF, an interaction I subsequently considered a de-normalising process in itself. Not many other children have a visitor who enquires thus about their life.

How are they interpreting the relationships in their world? Of what does their interaction with their parents consist? Although parents may be in accord with them, how does the child with CF interpret these relational dynamics? Perceived as a protective relationship, it is nonetheless tainted with the incongruence of collusion with medical carers and in the administration of the ubiquitous and uncomfortable therapy they dictate.

It is a bond in which love is demonstrated by this daily enforcement of arduous routine of physiotherapy and the like, one that children view from their own perspective, perhaps oblivious to the personal burden it places upon their parents. These are the ones who inflict pain, as Brooke confessed regarding physiotherapy: "It hurts when daddy does it". For Hannah, it is simply: "My dad will do it, but I hate it. It hurts." She had recently decided to substitute visits to the gym in lieu of this home routine. Tim was wise early on to his parents' ploy of game playing while he had his nebuliser, appearing happy to collude in an enjoyable and patent deception, which also meant he had their attention in the midst of each busy day. Little Grace is oblivious to the secondary function of her Christmas toy as a physiotherapy aide, so she plays along. When it is all no longer fun, just serious, hurting work, it will probably still be part of what parents do, because, for the older children, that's just the way it is.

Parents are a source of information, the framers of your existence, describers of your disease, creators of your impression of it, and the ones who couch your future in palatable words. By his father's admission, I was aware that Toby "wouldn't have a clue about life expectancy and all that sort of thing", because, for this little boy, his parents "worry about that enough for all of us", as they shield their child from

concerns in an attempt to maintain normalcy for their child. It was in the new-found world of budding friendship at school that Toby was beginning to reassess not only his disease, but also relationship with others outside his inner family circle, a risky situation on both counts, as far as he could see.

Regarding her son's condition, Ann stated: "I don't lie to him." Hence his realisation that he knew he "was different straight away." Likewise, Bob considered: "I always knew it," although his comprehension was in connection with repeated hospitalisations. None the less, he perceived that his parents "kept nothing from me." While parents of the younger children were posted in a protective posture around their offspring, one wonders if, inside this human shield, their children may be more aware than they convey.

It was opportune to have interviewed Tim in an afternoon and hear him describe his relationship with his mother as a "love/hate" one, and to hear her that evening designate the same relationship "very close." Was this the response of an unappreciative child, or a young man trying to recalculate the distance between he and his mother, in a usual separation experience in the adolescent to adult emergence? This process had been retarded when in his latter adolescent years, he had been denied the gradual appropriation of autonomy. "They are a lot more mature than a lot of other kids their age", Ann had told me. However, Tim's declining physical state meant that relationally he was in a negative down turn, and obliged to rescind many aspects of autonomous living he had attained. Independence is no use if you are sick. During that time, the woman who was "annoying" was now his main carer again, as he was obliged, in a sense, to return to the start, and wait to throw six. So his declaration of independence had to be emotional at that time, until post transplant, it could be declared via physical separation as well. It was understandable that Ann "got on his nerves" - she was in the wrong role for a young man of 20 years.

Transition to adulthood is discussed in the literature, but usually in the context of medical care, and the moving from child to adult services in this public domain (Fox 2002:3; Madge & Bryon 2002:283). Within the family, the adolescent relationship has been portrayed, like Tim's, as one in which parents are an integral support, but starting to be viewed as nagging, part of the support now being too much. However,

those with CF are less likely to emancipate from their parents (Raymond et al. 2000:362), perhaps a decision arbitrated by the young person's reticence or, as demonstrated in Tim's case, a corporeal conclusion?

By comparison, it was in early adolescence that Bob had separated geographically from his parents. This daily relationship was not immediately replaced by meaningful friendships at school, and caused Bob much angst. For Mark and Grace, relationship is still in the context of home. Toby is emerging to include those at school, while for Hannah, having widened her relational circle to encompass a school milieu, she has now retreated to her family circle, having gathered friends from the outside to join her within it.

Interrelationship can, however, be risky, confronting, and is moderated by the revealing of their CF status. Disclosure tactics of parents are reflected in those of their child. It is a process that is modelled and initiated from parent to child then to others, or directly from parent to others. Ian and Max had a 'no-telling' policy, reflected in Ian's clandestine behaviour, and not risking exposure on the school camp. Their mother obviously learnt from her family, who, when she was a child, must have agreed that they would not tell their visiting cousin from Tasmania.

Most participants commented on the fact that they avoided mixing with others with CF because of issues of cross infection with resistant "bugs". While the latest scientific literature is confirming this as a clinical issue (Al-Aloul et al. 2004:334), it is also a relational choice that reflects a desire to be located within a social situation deemed "normal." Avoidance of mixing with other families with CF is not only a medically-driven decision - the minimising of cross infection - but also a socially-constructed one, as Liz confessed: "You just wouldn't mix with the children that had CF ... I don't make it my whole life."

That one of Tim's close friends had been a fellow CF sufferer saved his needing to tell in that case. Not that that is an obstacle for him. He is quizzical about those with CF who could have best friends who are uninitiated into their having this disease, because as far as he is concerned, it is "nothing to be ashamed of."

But there is a risk. Once you tell people, they treat you differently, as Julie could attest. This risk-taking behaviour is inculcated from an early age. To tell or not begins at kindergarten, where snacks in a lunchbox are accompanied by menacing enzyme capsules. It is a process inherent in the life with CF, the arenas of disclosure always fraught with significance and expanding in influence.

When it comes to adults, Lowton (2004:184) highlights that there is 'little tradition of disclosure or concealment' for them to draw upon as a guide to different social situations. The young adults in this study have negotiated their own style, in a process that is moderated not only by how to act, but, more essentially, 'who to be (p.184),' a notion that is intrinsic to the maturation process anyway, but further complicated by this evolving process of disclosure. Admi (1995:496) designates a policy of telling as not static, being rather situational, noting that some CF sufferers utilise the strategy of harnessing a better known, less stigmatising disease to account for their symptoms. Bob, who devised his tactics in the harsh reality of boarding school, would say: "It's not an issue to tell people I've got CF". There again, no asking equals no telling as far as he is concerned. But, should an enquirer errantly believe that his cough is asthma, he will inform them of the correct diagnosis. This is a relatively easy exchange in what Lowton (2004:170) nominates a low risk, casual encounter. More careful consideration is called for in medium risk situations, most notably friendship. In the high-risk category, however, the consequences can be dire. It is in the domain of potential relationships - employers and partners - that the risks are elevated. Bob had successfully negotiated with the former for jobs. However, as I recalled his candid calculation of his genetic burden in light of procreation, I realised something of which he is no doubt well aware - the stakes are dangerously high with the latter.

One of the anticipated post transplant joys for Tim was the prospect that he could embark upon a relationship of a romantic kind, such an attachment now being a possibility when an affectionate kiss is no longer thwarted by paroxysms of coughing and tenacious sputum, with haemoptysis being described anecdotally as an absolute passion killer.

Relationships are a difficult component of maturation, being more complex for those with CF. Those in this study have depicted a process of relational circles that expand

at times, and at other times constrict, generated by measured desire and risk of exposure. Hannah spoke happily about her dream of a long-term relationship, plus children. Likewise Bob's definitive "my wife" included children. Such reactions are in contrast with the despondency that has been reported in response to adolescents learning their future potential in these matters. Bob's mother had told him that he would be infertile. But in this era of rapidly developing medical technology, assisted reproductive procedures (Stuhrmann & Dork 2000:71) are, like lung transplant, something of which Clare now says: "That's a possibility."

This is tainted, however, by Ian's plaintive admonition to his girlfriend to seek the company of someone else, someone with whom she would have a potentially more customary future, because he considered he would not. Did he have insight not only into his reduced lifespan but also into his probable infertility? At 13, he is in the age bracket recommended as the one at which to talk to boys about the latter. Or will he have to wait until he is 15.2, the usual age it actually occurs (Sawyer et al. 2001:36)? I suspect that hints, if not facts, came his way during his Melbourne sojourn, and may have contributed to his being "a new kid."

### **Bridge building**

Hannah spoke of hospital staff with great familiarity, using their names as friends. She considered it weird that "people in the hospital know me from when I was little", an innocuous statement initially, but not when "some of my family members don't."

Most of the professionals Hannah referred to by name were nurses, with whom she obviously enjoyed positive relationships. Where were the nurses in the accounts of other participants? Mindful that my query of living with CF was originally posed by nurses, where have they figured in its response? That they are subliminal, if not sometimes invisible, means they do need to know more about that life because they would seem not to be overtly contributing to it. Where are they? What are they doing? Where would I expect nurses to intersect with these children's lives? Conspicuous by their silence, their voice is paradoxically heard loud and clear when controversial or erroneous. Hence Toby's father recalling the child health nurse who ardently declared: "They've got it wrong ... I wouldn't do what they say."

Relationships with nurses is a feature of the diagnostic phase, wherein they project lack of complicity onto novice parents, rather than onto the baby's body. They then step into the background, emerging now and then with inane comments such as: "When did he catch it?" 'Holders of hope, bridge builders' is how nurses are depicted in a British study (Hodgkinson & Lester 2002:377), which nominates them the first people mothers turn to with concerns and for the interpretation of medical information. This would seem to describe a relational potential.

Echoed in the question nurses have entrusted to me is, I begin to see, a desire for relationship with those living with CF, within the context of which, rapport is established and knowledge of an insightful kind generated. An adjunct would be the resultant desire and need for nurses to keep abreast of current trends in CF, a process in which they will not always be the authority, as it is acknowledged that parents and their children with CF often become the expert (Tippl 1995:127), a fact reiterated by the original physician in Toby's scenario. The potential for therapeutic relationships is not only immense, but is also a two-way exchange.

As Brian sat in the ICU with Tim, he sensed that the nurses were avoiding interrelationship by focusing on tasks, interacting brusquely with him when trying to retrieve the key to his sleeping quarters that he did not want to relinquish. By contrast, it was a nurse who spotted Mark's mother's weepy retreat to a secluded corridor, speaking with insight as she acknowledged Dianne's distress. Held in high regard are "the ones from Melbourne", who by presenting as well-informed members of a team and having up-to-date knowledge, instil confidence, and are definitely 'holders of hope'.

### **Relatively so**

While some parents in this project had reported decrying and apportioning blame over their child's disease status, their children with CF did not convey any similar recourse of culpability. Nor did they express the wish that they had not been born, the life with CF apparently not being a comparison with no life at all.

Their parents are the gatekeepers and protectors, the interpreters of that life. As far as the child with CF is concerned, they are also colluders in treatment and the ones who

transmitted the disease. But they are the ones from whom to wrestle understanding and importantly are there when prized independence is to no avail

Life with CF is no solo performance. Of necessity, it is enacted with a cast of main supports, who are sometimes centre stage, at others hovering to the side, waiting for their next cue, but never able to leave the stage. There are also those poised in the wings for intermittent, seemingly short, appearances, their contribution to the dialogue being nonetheless integral to the action.

Parents are committed to the performance, learning their lines with fervent accuracy. Others, such as extended family and friends, sometimes appear to be confused as to what role they have been cast into. Some medical personnel would seem to deliver their lines more as interjection than key links in the drama, needing the services of the prompt for their delivery.

This study is congruent with the constancy and complexity of relationship as portrayed in the literature, but further heightens understanding by going beyond the scholarly borders of more structured studies. Relationships for the participants in this study are moderated by the fixed geographical borders of the island setting in which they are encountered, while, as their narratives disclose, relational borders are subject to negotiation, governed by others being privy to the knowledge that they have CF.

The most immediate relationship is that between those with CF and their body, a liaison of the most intimate kind.

## **Form**

Foundational to CF is the child's form, the body being the site of disease, and necessary for existence. It is now labelled, quantified, assessed, under surveillance and stamped with a 'use by' that will surely, relentlessly, run out long before the normal expectation of 'three score and ten'. Owners are proffered no warranty. It is inscribed with much more, however, the life with CF existing well beyond the quantified parameter of its housing. The body is more than an apparatus, albeit a

defective one which caused the problem in the first place. Not objects, but 'ongoing stories', writes McDonough (1998:6) of the CF form, including his own. He adds: 'Our bodies *are* the story. What happens to us comes from our bodies ... Every one of us is a walking story, unfolding with the narrative drum of heartbeat and blood and cellular respiration.' What saga has been assembled in the narratives, poems and pictures with which I am dealing? What tales do the bodies of the children in this study tell? They are fables of a body that is one moment explicit, but in another is implied. The child's body as diseased has initially become visible as a malfunctioning unit, appearing then disappearing throughout the various accounts.

'Nurses need new ways to understand the body', writes Wilde (2003:173), adding 'outmoded views of the body objectified as diseased or unmanageable deny possibilities for growth and affirmation for those living with an altering embodiment.' By reconceptualizing the body, she aims to render it more 'user-friendly', not only empowering its owner, but also carers, by recognising what it can offer, when both sick and healthy. Wilde takes the biological versus lived body concept to a new arena, in which an ontological refocus considers the body as 'friend' and 'silent partner', while an epistemological one designates it 'informant', a divulger of information. The former speaks of compliance, and the latter an exchange that may not always be with permission of the owner, a case of the body telling its own story.

I considered the children in this study. Before diagnosis, their bodies were playing informant, hinting at a subtext that manifested in such ways as failure to thrive or meconium ileus. Following diagnosis, a labelled form was on the one hand devastating, but on the other, an alleviation of distress for those parents who had contested indeterminate symptoms (van Manen 2002:8). Surgery performed and diet amended, energy could then be focused upon bringing the child's body back into line, steering it towards physiological function, and establishing it as a 'silent partner' for as long as possible.

As in any relationship, however, the other party cannot always be relied upon. For those with CF, their body can be 'risky' in social encounters (Lowton 2004:171), not always colluding in concealment, by a mistimed, uncontrollable cough, for example. This is a problem of which the younger children seemed unaware, their bodies



appearing still to be in relative submission to the daily disciplining with physiotherapy and medication, still responding to activity demands, and still able to be counted on in public. But Ian, for example, was not only starting to appreciate the discrepancy between the image in his mind and that in his mirror. He could also see that he was not in step with his school peers. Thus he attempted to stifle the aberrant story that his body was beginning to tell. It was in the company of Melbourne CF peers that he could reconsider his body in a context in which he was free from the pressure of having to harness his form into unified public agreement. At primary school, Tim enjoyed the harmonious co-operation of his body in athletic ability, until the whistle blowing haemoptysis incident. Van Manen (1999:xv) describes the 'wayward body' of the person with an illness. Rather than errant, is it not conversely compliant, conforming to the genetic script with which it is programmed?

At this juncture, Grace's mother declared her to look "normal", and Brooke could be proud of her "nice legs". Hannah's body, by contrast, was spreading too vigorously beyond her imaginary designated borders. She was working hard with the gymnasium routine to shrink it down, against her father's insistence that she feed and nurture it as he wanted her to do, according to the quantified proportions towards which his care had been directed.

For these adolescents, the immediacy of their body image seems paramount. Acceptance and self-esteem are derived from their current form, not some surreal futuristic model that they have yet to attain, a conclusion that is congruent with the current literature, wherein it is documented that not being different takes precedence over compliance with medical regimes (Willis et al. 2001:1165).

Brooke chatted about her enjoyable bike rides, Bob reminisced about his sporting prowess at a similar age, and Tim recalled starring in junior athletic competitions. For a time, the disease was masked by normal performance and the body appeared compliant. It was when usual expectations dwindled or ideas of average eluded, that the body became informant, and the child - and parents - were confronted by it. This served as a reminder that CF does not go away. It is not grown out of, but rather grown into, as increasing time correlates with exacerbating signs.

So begins a new phase of relationship with your body. It cannot be trusted to be in tandem with you. This body could give the game away - a theoretical, third hand supposition that gradually becomes a probability, heralded by initial inklings. This body could let you down after all, and in fact is already starting to do so. Lowton (2004:171) describes 'lapses of bodily control' that must be avoided.

Bob had devised situational options should his body emit a cough. There would always be suspense in an encounter, rendering an inherent lack of control. How much autonomy did he really have? His mother perceived that, with reference to body care: "He does everything now". While the parents believed they were relinquishing control and that their offspring were assuming it, it was really the child's body that was subtly appropriating it. No matter how stirring a story the life tells, it is enacted in a prematurely aging and self-destructing form (Hillyard 2001:S20), its finale by virtue of the fact that the body has the last breath.

### **Equal shares**

Shared embodiment is a concept that has diffused the participants' reflections. The initial sharing, the endowment of the CF gene, beginning a life within which parent and child remain inextricably linked, with the child never really taking possession of their corporeal self. While the parents purported a considered releasing of the care of this body with CF to the young owner, their maintaining ongoing vigilance over it potentially thwarted this process in which they, as it were, retain the title deed. Handing over being rhetorical rather than actual, the deal would probably only be sealed with vacant possession. Clare considered the transaction as being "just too hard to let go of those ties when you have been the full carer of the child, and you know every little detail - bowel motions and everything - because it's been important, and you have to let go."

There is a pervading sense of the children's body never really belonging to them. Their parents perform the ritual of physiotherapy, and are involved in corporeal functioning. They are still bothered with care imbued with an emphasis that goes beyond the usuals of brushed teeth or not staying up too late. They juxtapose these with essentials of sputum eradication, enzyme ingestion, and the pursuit of the most efficacious breath. Even "breathing for him", as Tim's mother had said, standing in,

in a quasi *locus corporeal*. It is as if the parents, particularly mothers, of the CF child remain pregnant with their offspring. The intensity of concern and nurture that began for them *in utero* was exacerbated in the pre-diagnostic phase, and translated following this into the chronic incubation they now continued. Ann wanted to breathe for her son. When she saw him for the first time post transplant, she exclaimed at his pink fingers and toes. How like a newborn, seeing a body that is known, and yet viewed for the first time. It was like a new body. New lungs took new breaths. "The gift of new life ... A brand new life" was how Tim had poetised it.

While those who suffer an acute illness episode are confronted with a sudden awareness of their body, Tim had lived through a preoperative era wherein his body was on the one hand his own, but on the other, was in a state of physiological communication breakdown. This dichotomous perception van Manen (2002:3) would clarify as Tim experiencing his body 'as alien while undeniably himself.' For Tim, it had been the gradual alienation of his body winding down. There was no re-acquaintance with self in the post-operative phase. Rather, it was adaptation to a mode of function that surpassed any he could remember. It was also familiarisation with part of somebody else, a transitional time signified by his using the objectifying expression "the lungs" to refer to the organs that he was absorbing into a redefined 'liveable relation' (p.3) with his body. He had been entrusted with a component of another person. But saying "her lungs" would not help the incorporation process. Ann reflected: "As far as thinking it's something alien in his body, I've never, ever thought that ... I don't think he has either." For Tim, the true alien body is his own.

He had formed a new relationship with his body. Now as a 'silent partner' (Wilde 2003:173), it could be counted upon in a social encounter, and for a time, he could indulge in the novelty of forgetting - 'the smoothness of forgetfulness' (van Manen 2002:9) - when it comes to breathing anyway.

However, he now viewed his body in a realistic, albeit humorous, self-deprecating light. He joked that "I can't go topless anymore. My big, ugly scar [would] scare people." His body had survived 21 years of living with CF, during that time passing through the anticipated phases. It was now inscribed, carved with a record of achievement, a map indicating not only the way he had journeyed, but displaying for

others the projection of possibility. Now with an expansive cuneiform scar adorning his chest, CF is no longer concealable but is now on blatant billboard display.

Others in Tim's scenario had vicariously shared his embodiment. His father's body had absorbed the pressure for two. Stressed and depressed, it attempted to soak up and carry away the strain of those transplant weeks, or perhaps even of a lifetime.

Kate and Pete divulged their bodily participation in the illness routine, being "both on blood pressure tablets and both fairly stressed." Treatment and body-taming extended beyond Toby's, as they corporeally shared the CF experience with him.

The notion of sharing sometimes went beyond the vicarious, to that of substitution. Tim actually enunciated the desire to stand in for his deceased friend Sam: "Take me instead, please," he poetically pleads, while anything that happens to Toby is "going to be over my dead body" as far as his father is concerned.

### **A hands-on approach**

Ann surprised herself when, upon first hearing Tim's diagnosis, she was unable to handle or hold her child. Notions of connecting with the child's form by touch and handling have been woven through the participants' narratives. They are actions that family and friends were reluctant to do, causing distress for Clare and anger for Dianne.

Bob would be unaware of his mother's emotional wrangling between efficacy and affection, wanting to proffer her hands for comfort and holding, rather than remedial instruments applied at a rate and force outside the nurturing range, but inside that deemed therapeutic. The continuity of hands was not broken for him upon his departure to boarding school. The matron went *locus parentis* in the physiotherapy regime and the laying on of therapeutic hands.

It was her parents' hands that held Grace on the x-ray table, all for her own good, as the hands lovingly crushed down on the terrified, screaming form. Were the subtleties of intent lost in the translation? Likewise the daily physiotherapy pounding, which both Brooke and Hannah reported as hurting, particularly at the strong paternal hand.

That hands are also devices of discipline perhaps meant they had interpreted the daily percussion as some subtle punishment for living out of line.

The child's body remains the arbiter of relationship, the designator of years, and the focus of fight. The future is actually in its hands.

## **Future**

The future is initially cancelled at diagnosis; and then becomes an extending horizon, moderated by new treatments and the child's response to these. There is an inherent sense of loss of future, and finality. Pete knew that: "CF will surface. It will get you in the end." Tim had lived his childhood in anticipation of the 15 year milestone that denoted his demise. Surpassing this had projected him into what had previously been an indefinite future. "Extra time" was how Ann described the redefined prospect following transplant - "got his life back" - and Tim could plan, in fact, he had "a list of things to do."

And what of the younger children in this study, who had been born into subsequent eras of diagnostic strategies and mean survival predictions? Dianne had told me: "I think about the future, but the future will take care of itself. I'll think about that when it gets here. Yes, a day at a time. That's all I can do. Because Mark could die tomorrow. You just never know."

At two, Mark was too young to talk about such things. I wondered how he would envisage his future when he is older. The adolescents and young adults painted future scenarios that not many years ago would have been deemed fantasy. But the carrot of projected new treatment and the elusive cure, plus human optimism in light of increased survival statistics, has permitted them to dream. Said 13-year-old Hannah: "I want to get into uni and all that sort of stuff. I want to have kids. I reckon being a chef would be cool ... I want to succeed in something."

A common theme in the current literature is that of CF coming of age, having been considered a childhood disease (Lannon Palmer & Boisen 2002:45), and now

redefined as an adult one. There is an emphasis on transition to adult services (Lewis-Gary 2001:521), and the mode of delivery and efficacy of care (Madge & Bryon 2002:283). At this stage there are minimal complimentary studies regarding not only adaptation to the adult body the incumbents once may never have had, but also the future for which they may have only tentatively planned. Described in the literature as enjoying strategising “specific goals including graduate school, marriage, career advancements and travel” (Lannon Palmer & Boisen 2002:53), the young cohort with whom I talked reflected such a focus. This is exemplified by Hannah’s desire for career and travel, albeit a contrast with her current denial of her designated corporeal future in regards to dieting and body image.

Bob is certainly a young man with plans for career and family, tainted, however, by his plaintive: “I don’t know if I’ll get there ... I trust I’ll get there ... Long way to go yet.” For now, Grace’s horizon of the future extends to starting school and being older than Bronte. She is innocent of the fact that one day, Bronte will no longer be the younger, but the only one at all.

Ian had signified his ready acceptance of his cancelled future by verbalising this to his girlfriend. However, his revised version following the imbibing of contemporary facts plus peer enthusiasm in Melbourne, rendered him a revitalised approach to his everyday world.

While the future may be off in the world of tomorrow, for these young people, it is tentative, like some reward for diligence and compliance. For adolescents, this is moderated by peer group pressure and seeking to belong, acceptable risk on the school camp now, being a more valid construct than a fictitious future. Interestingly, for all the trauma and actualisation that lung transplant had afforded Tim, he confessed: “I am taking my rejection medication because I know if I don’t get that, it will kill me ... Like I know with these other things they help me, but I’m not going to die if I don’t.” With an extension on the future, he had assessed that he could relax a little on the medication. After all, he considered himself “not sick anymore,” and probably going to experience a once elusive future that had now become a provisional present unencumbered with the regalia of his past life.

The outcome of CF is a *fait accompli*, even the ‘when’ being calculated and published. What would it be like to see your life written about and projected?

Discussion of adulthood and the end stages of CF in the literature centres on preparing for death via palliative care (Lowton 2002:142) or maintaining a combative stance while awaiting cadaverous lungs (Ferrin et al. 2001:61). As the young people spoke with me about their future, they invested it with life, plans and options. Those who had witnessed the cancellation of a friend’s future by death did not mention their having factored this into their expectations. In fact, Tim emphatically had no time for that, he has “too many things to do.”

### **Further possibilities**

With regard to fertility issues, the phrase ‘loss of biographical possibilities’ (Boughton 2002:423) has appeared in the literature. A concept that received little attention in the conversations I had, participants conversely spoke freely of planned children, no doubt aware of the potential that recent advances offer (Stuhrmann & Dork 2000:71). Bob’s mother could recall telling him he was infertile. Is she aware that his planned future is populated with children, and a wife for whom genetic assay would have sealed the relationship (Emery 2001:84)?

Such deliberations would be a mixed blessing for continually-caring parents. Joys of grandparenthood may be marred by the knowledge that their child’s premature death would precipitate issues of caring for *their* offspring, as discussed in the literature (Walling, 2002:2583).

While children dream, their parents hope, the only recourse for those fighting on behalf of another, in the midst of uncertainty. They are people-in-waiting - for breakthroughs and cures. Nigel is expecting that the genetics he has studied will come through for them. Liz knew that although five years ago a cure was five years away, it was only a matter of time, hopefully. Others waited in anticipation of a different future, not full of maybes but furnished with certainties. Clare had heard the “wonderful stories” about transplant successes. Several parents stated that they shall, as Stuart has decided to, “look to the future.” How else can meaning and purpose be ascribed to the daily burden of living with this disease?

Is it also because, as Cathy thought: “It’s a long way away yet”? But even this mother of a four-year-old qualified that with “hopefully.” She added: “We still worry about what the future holds, as every parent worries about the future, as far as your kids are concerned.” But other parents do not have a designated disease trajectory, and can imagine a fabled three score and ten years for their progeny, rather than a potential forty (Elborn et al. 1991:881). Despite being delivered a different prognosis, treatment options and possibilities, those starting out living with CF are as concerned about the future as those who have lived through many more years and trends. A lifespan projection that has gone from eight to thirty in as many years (Elborn 1998:217) is still not a proper amount. No parents stated it, but if a researcher can read between their lines, it is simple maths, uncomplicated odds, to know that it is highly likely their child will die before them. These parents can plan more future for themselves than for their child, who will probably not be in the picture. It is a future that is already detracted from. Thus it will be devoid of both the person and of the encumbrance of care. Will it be remembered as such a burden then?

All they can do is, as Pete decided, “Your best ... If your number’s up, well your number’s up, and there’s nothing we can do,” which seemed a glib call after some aspects of the candid conversation in which we had engaged. Or was it an acknowledgement that the finale is numbers, and their son will end up not only with an epitaph of memorable phrases, but also a permanent numerical representation in an official register, wherein his number will enhance the median age from which subsequent parents will draw their futuristic assumptions? So his number will never really be up.

There are those described in the literature that are not, as it were, sitting around hoping. They are scientists whose work constitutes the bulk of discussion around the concept of future (Doull et al. 2001; Elborn et al. 1991), and upon whom parents are relying. Bob’s are confident that, when gene therapy becomes available, “we’ll be told.” I wonder where they will get their information?

Although the parents certainly placed great store by the insights to be generated by this project, I suspect that the research results on which they are really waiting are those that will herald scientific breakthroughs. Amidst articles on genetically



modified mice and their role in the development of drug therapy, CF and spina bifida are placed at the forefront of those diseases that will be 'cured' (King 2004:7). What is it like to be correlated with a mouse respiratory tract? Possibly novel, and no problem if it will help?

Recent granting of restricted licences to utilise human embryos for stem cell research shifts the emphasis of ethical debate, it being somewhat salved by the altruistic outcomes proffered (Dayton 2004:3). But in the world of those with chronic illness, is it a different debate? After all, Max was an embryo subject to further investigation, the deliberations potentially falling either way. Should he have been the victim of the alternative outcome, Ian's life would have been markedly different. As it is, they are brothers with unique questions regarding future existence, 'who will die first?' being one of the more stark ones.

Life for adolescents with CF has come a long way since the little girl in the 1970's whose declared goal was 'to become a teenager' (Tropauer et al. 1970:427). Their plans are nonetheless infused with an uncertainty and detracted from by mean survival death rates that would discourage an unending Utopian regarding of the yet-to-come.

The future can be extended by 'there's always', a notion particularly considered by younger children's parents. Bob's mother is pinning her hopes on a lung transplant. But for Tim's, there is nothing else at this stage except some mice respiratory tracts and embryonic stem cells (King 2004:7). In amongst his plans, there was not an obvious timeframe. I wondered how long he imagines his future to be?

A future with CF is paradoxically certain. Death will be premature, will be in a certain age range, and will be by respiratory failure. Stuart talked the most openly about death, half expecting it as a reality. "You never really sort of talk about it but that feeling's there ... Is he laying in bed dead?" It is because of such blunt realities that Ann believed these children negotiate life with an advanced maturity and are "more understanding," a notion documented in the literature (Lannon Palmer & Boisen 2002:53). Bob knew he is "the one in four". No doubt he is aware of other odds, but as far as future plans go, he gave the impression of being willing to take a gamble on those.

Yet, in spite of knowledge of these facts, the young people with whom I spoke conveyed an indulgence in the idealism of youth. For anyone, death is always one breath away, but those with CF have an idea of when that might be, and a certainty of how. It is a life lived with an end that is both scripted and expected, although continually subject to redefinition.

At birth, the child is an embodiment of the future, imbued with a sense that they will be generational. Toby had not even graduated from baby to the title 'child' when his future was cancelled, and by their words, medical carers were "taking him away, like he's not going to last the distance." When all is said and done, Pete concluded: "[CF] will get you at some stage."

Is the future so different for those living with CF? After all, there are no guarantees in any life, only unwritten suppositions. As Ann contemplated: "I could have been blessed with a perfectly healthy child who walked out in front of a bus." But that is a random, unforeseen occurrence, and one that is not predicted, documented and subject to scientific scrutiny.

## **Philosophy**

Parents and older children with CF had a philosophical one-liner upon which they drew in order to make sense and derive meaning from their experience, and to give credence to it all, an attempt at 'don't let it all be for nothing'. "That's life", sighed Cathy, and the parents of the other younger children reflected a similar resignation. Contemplating the premature mortality of her two-year-old, Dianne acquiesced: "If it happens, it happens ... it was meant to be." This sentiment was echoed by Ian and Max's mother, "It was meant to be" actually referring to Max as well as the CF status of her sons. She had moved on from acceptance to a dual philosophy, now getting on with life. "Just do it," she added, having had more experience of the life with CF, and a consequent realisation that there is a "bright side" upon which to direct an alternative focus.

Nevertheless such sentiments eluded Ross. He simply stated: "That's just the way it is", a declaration of a temporary truce with not only his daughter's disease, but also with those engaged in the fight against it with him, who paradoxically sometimes seemed to be firing at him from an opposing stance.

Liz was still concentrating on "one day at a time", believing "grieving over something that hasn't even happened yet" to be pointless. Others devoid of these thoughtful tenets waxed metaphorical or utilised cliché, the tools employed by those unable to find adequate ordinary or medico scientific words through which to realise expression.

In this project, metaphor has played an important part as a communicative device. How else could Stuart, for example, convey to me the gravity of the young people with CF he had witnessed alighting from the plane after their trip away? I recall his facial expression as he reconstructed the spectacle and emotions so that I would understand and could have an inkling of the intensity of the revelation that had dawned upon him in that encounter. "Like kids coming back from war with a special understanding of their mortality and making the most of life" was an extremely effective metaphorical device.

Described as 'understanding and experiencing one thing in terms of another' (Wurzbach 1999:94), metaphor is both a way of framing experience and of communicating it (Jairath 199:284). It is a means of picking out parts of experience and treating them as discrete entities (Lakoff & Johnson 1980:25). Thus bounded, they are afforded some sense of definition in a lifeworld that may be temporarily scrambled and bereft of meaning.

It was during a break at an international CF conference that an earnest father told me: "In the cocktail of life, you have to get all the ingredients right," a surprise to me at the time. His being a military man, I had anticipated his speech would be couched, as was his approach to CF, in combative terms. But perhaps the power of metaphor lies in the selection of language and imagery well removed from the user's vernacular, the lingual detachment facilitating a concurrent emotional disconnection.

For Ann, life has been a “roller coaster ride”, Kate and Pete felt as though they were “getting blood from a stone”, while for Brad, CF was “one big question mark really.”

At some points in the conversations, there were no frameworks through which CF could be readily defined. When such statements eluded them, many of the parents resorted to the ‘there’s always someone worse off’ scenario. Illustrating it with extremes of medical calamities, they calculated CF to be not quite so bad when grouped with being “born without any bones in the fingers” or “run over by a speedboat.” Literal analogies were used in a comparative interchange, as the substitutionary sifting of metaphor was momentarily abandoned, and CF examined for its stark reality, albeit in comparison with another actuality, so that it is not the very worst one that could happen to you.

Ann had had 21 years of meaning making. Having had this long at “getting on with it”, she told me that such things as CF “come to you as a challenge. It’s experience that life gives you, and what you can take out of it afterwards is what you really learn.” She then served me her whole cache, a multiplicity of metaphor and cliché, of buses and bridges:

*I’ve always been a very positive person and I believe I’ll cross that bridge when I come to it. I could have been blessed with a perfectly healthy child who walked out in front of a bus and was killed. So I’ve always taken it day by day, and I’ve always stressed that it’s the quality of life, not the quantity of life.*

She concluded that CF had made her “the person I am today”, a declaration that can only be made by a retrospective glance over accrued time.

It was fascinating to then speak with Tim’s stepfather, Stuart, and to hear him reiterate the same philosophical approach to the deep experiences that life with CF had rendered them. Stuart’s: “If you don’t look at what something teaches you, well, what’s the point of going through it”, was reminiscent of his wife’s philosophy an hour before.

I noted that Tim reflected the philosophical stance of his parents. No ‘why did this happen to us’, or other blaming tactics, he likewise invested his having CF with a purpose - “for a reason”. Does he know what that is, I wondered? He continued: “Because whoever decides people’s fate thought: ‘Well, he’s strong enough to cope with this problem.’” I considered the corollary, to have lived a substantive part of your projected lifespan and be unable to endow it with either rhyme nor reason would seem a waste.

Tim had factored in a quasi-religious personification of “whoever decides people’s fate.” In contemporary western culture, writes Czechmeister (1994:1230), people have often lost the meaning offered by a religious faith, with the result that metaphor and symbols, particularly in relation to life-threatening disease, become even more important.

For Bob, however, his faith in God provided an anchor in his lifeworld that seemed to obviate his need to use any symbolic framework to make meaning of his experience. Devoid of metaphorical embellishment, his narrative was infused with a future purpose rather than reflected upon in search of a reason, the result of contributing his *raison d’être* to God. This was not only a reflection of his parents’ beliefs, but also came across as a strong personal conviction on his part.

I had undertaken unstructured conversations with the participants in this project. Thus there were no specific questions posed. Nonetheless, common patterns of telling emerged. In the midst of deep expression and the relating of daily living with CF they would present me with their philosophical reasoning. It was as if telling the previously unreflected meant assessing it against such a stance in order to make sense and derive meaning from this exceptional life.

### **Meditation on a theme**

Fear has been a hallmark of the life with CF, from Tim to Mark. All have been engaged in a battle *royale* for normalcy, information, for life itself. This has resulted in their being shifted from “here to there”, in a morass of movement and activity that

has precipitated the forging of a distinctive relationship between parent and child. This bond is often strengthened in intensity as other relative connections are weakened, and friends selected and rejected. Such are the strategic necessities when life is housed in a form that is 'programmed to self-destruct' (Hillyard 2001:S20) in a not too distant future.

Tim has blazed a trail, having gone where he might never have imagined when he was Hannah's age. What pictures would he have drawn as an eight-year-old like Brooke? Conversely, what poems might she write when she is 21?

As has been evident in the participant's narratives, the two decades separation from youngest to eldest has not rendered a corresponding divide in experience. Having discussed these dynamics in detail, the foliate themes of fright, fear, fight, flight, familiarity, form, future and philosophy are patently characteristic of the life with CF. They have highlighted that experience, their accentuation bringing the phenomenon to light, which is the focus of the ensuing chapter.

## **A panoramic perspective: phenomenon portrayed**

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Whenever you go out to paint, try to forget what objects you have in front of you - a tree, a house, a field or whatever ... Merely think, here is a little squeeze of blue, here an oblong of pink, here a streak of yellow, and paint it just as it looks to you, the exact colour and shape, until it gives your own naive impression of the scene before you.

-Monet

I have endeavoured to portray the phenomenon of living with CF by presenting various perspectives. Each participant's contribution is an original, not a reprint but rather a fresh depiction, delivering a different aspect of a particular scene.

Having explored and described these data by tracing the branches of time, body, space and relationship (van Manen 1990:101), the resultant process of foliation has yielded the sub-themes as discussed. Examination of the leaves necessitates a consideration of the core aspects of what might be the trunk of the plant, and then, of what the root consists. If my phenomenological description is 'an adequate elucidation' of the lifeworld of those living with CF (van Manen 1990:27), the phenomenon will be exposed.

### **Relative similarity**

Having collated this patent set of sub-themes, I considered whether they are discrete to a life with CF, or would they superimpose neatly over the lifeworld of those living with other chronic conditions? Had I captured the essence of a unique life?

I was aware of the subtle difference between those themes van Manen (1990:106) dubs 'incidental' as opposed to 'essential' and exclusive to the phenomenon under investigation. In my initial perusing of the literature, I had encountered various childhood chronic illnesses which were sometimes featured alone, but often in cohorts with others - including CF. I could recall remarking upon certain similarities with CF, such a sentiment being diffused with a 'but', as comparison would dwindle in the face of life and death outcomes.

Like those with CF, parents of a child with diabetes mellitus, for example, are described in the literature as grief stricken following diagnosis, and subsequently coping with ongoing sorrow as they 'come to terms' with the fact that their child has a chronic illness, a condition in which resultant treatment and perceived losses are designated life-long (Lowes & Lyne 2000:41). It is here that the contrast deviates, being a matter of semantics, the notion of their child's life being followed by the word 'long' rather than 'threatening'. Their children are pictured adapting and adhering to various degrees (Conley & Kubsch 1997:548). Their disease is considered in the extent to which it is a threat to social wellbeing (Kyngas 2000:549) as opposed to their very being, as that confronted by the young person with CF, who is locked in the bind of a life and death struggle. For them, social death can precede physical cessation (Rozmovits & Ziebland 2004:187), as a recalcitrant body gradually becomes unreliable (Lowton 2004:171) and ultimately expires.

Consideration of children who were failing to thrive delivers several commonalities (Thomlinson 2002:537). As with CF, parents report initial relief at diagnosis. Likewise they experience tension between always monitoring and allowing the child to experience life, ultimately ending up as experts of the daily routine. Just as with diabetes mellitus, correlation ends here, however, as parents of the child who is failing to thrive gear up for a life that once again might be arduous, but probably lengthy.

'Unique challenges for care' are ascribed to both children with CF and those with spina bifida (Sawin et al. 2003:173), the most widespread physical disability, occurring at a rate of 1 in 5,000. CF is the most common life threatening genetic disease, but has double the frequency of occurrence of 1 in 2,500. Divergence begins by virtue of the numbers.

As embodied experience, spina bifida and CF are in direct contrast. The child with CF is born with an initially apparently normal body - although with an inherent defect - that gradually declines to a pathological state. Children with spina bifida, conversely, begin life with obvious medical problems that often set them on a course of surgery, followed by rehabilitation, the goal of their successful transition being 'competent independent adults' (Sawin et al. 2003:182) albeit often 'underachievers in independence, education and employment'. Thus an overtly defective body is



harnessed into a semblance of reconstructed normality. This child grows up with the assumption of becoming an adult, but not competent, a diametric opposition to the child with CF.

Although for parents of children with alternative chronic conditions there may be fright at diagnosis and fear of the implications thereof, I do not imagine these parents in mercy dashes for treatment. Their child may have a diagnostic label, but it is one that proffers lifelong service rather than the prematurity accorded more perishable items.

Those with other chronic conditions may sometimes display leaves of thematic similarity. They are not, however, a branch from the same trunk, nor sprung from the same lifethreatening status that roots the child and parent into the experience of living the life with CF.

### **A matter of life and death**

While no leaf is identical to another, they will manifest a commonality of characteristics that enable an observer to identify the species of plant. Thus I re-examined the sub-themes I had accrued, and a concentration of qualities became apparent, obviously indicators of the essence I was seeking to clarify.

By way of reiteration, philosophical framing has represented the concerted effort on the parents' part to make sense of the death sentence that has been pronounced over their child, and to reframe their life as a result. For their child, the concept of future was one initially cancelled and then moderated by impending premature death, life being intermittently extended and redefined.

And what of the child's form? On the one hand it hints at potential death with symptoms and hindered function, and on the other, it is the focus of concerted effort to foster life.

But as I have discussed, it is not only relationship with the corporeal self that is affected. That with family, friends and various others is also disturbed and disjointed

because of this dynamic of imminent demise, while concomitantly encompassing those committed to maintaining and extending life.

Participants have all described flight, representing escape *from* death, and *to* life-saving treatment and care. Intrinsic to this is their fight *against* death, being manifested in the fight *for* life.

I can only imagine the subtly attendant fear of death itself, or, conversely, dreading the absence of life. Not knowing when that will be, but just having to confront it is the biggest fright imaginable. Several parents described it as the worst fright they have ever had, as the concept of life and death switches from being generically implied to being at the forefront of daily reality. The co-presence of these two dynamics apprehends those with CF in *a life and death binary* that infuses and is the essence of living that life.

#### **A core connection**

It was by tracing the branches of time, body, space and relationship (van Manen 1990:101) through the participants' accounts that I came to the sub-themes on one hand, and the essence or root on the other. I considered whether there was a pattern of certain existentials being neatly connected with definite sub-themes. But, on further reflection, it is by means of those four configurations I have come to a diffuse display of foliage.

What interplay connects the leaves and branches with the binary root? Composed of paradox and contradiction, it is the dynamic of a life of uncertain health, future and length, yet one that is overshadowed with the documented certainties of the outcomes for others. It is an existence in which energy is expended in the constant negotiating of normal and different, the children particularly, being in a continual process of camouflaging the latter with the reconceptualized former.

In several ways it is a concentrated life. Not only is a lot packed into a short timeframe, but it is also subject to intense focus and therapy. Paradoxically, the young people are simultaneously growing up but growing old, as their body ages prematurely. So Tim has achieved a duality of adulthood and middle age, according

to current predictions (Gibson et al. 2003:918). How contradictory it must be to live with such a contrary disease.

Being “all at sea” was how Clare conceptualised the outworking of this life and death duality, one in which parent and child are bound together, in a double bind.

Encapsulated in her expression are the realities of coping amidst unpredictable seas and often uncharted waters, when waves toss and sometimes engulf, all effort going into staying afloat. Particularly poignant is the parents’ struggle in the search for new and accurate bearings - of information, support, and services - that are within their range. Their new reference point is the external reality of confronting life and death on a daily basis. Although not always conscious, it is nonetheless implicit in the execution of each day’s routine of living. For the child, it is the coming to the realisation that in spite of their parents’ efforts, ultimately they negotiate these unknown waters alone.

### **Fresh focus**

When my nursing colleagues were posing their original questions, assorted inklings came to my mind as to what the life with CF entails. Having decided to examine this phenomenon, I considered further refinements of those thoughts, some elaborate, others ordinary. Even while subsequently isolating the foliate themes, I had been preoccupied by gazing at the complexities of the parents’ and children’s experience. I had not realised that it would be essentially a matter of life and death.

With such a conception comes heightened understanding enabling practitioners caring for those living with CF to look afresh at them. The desire to know what life is like for them at home may have been satisfied on some counts, where it has been confirmatory of supposition, but stirred to re-conceptualisation on others, as exposed truths and impressions convey a unique glimpse of a lifeworld that may not have been as the enquirers had imagined.

The need to respond was initiated. With a subtle realignment of focus here, and a readjustment of attitude there, care can be delivered from an empathetic bearing towards those for whom it is not so much a bothersome routine, but a life and death imperative.

From the opening chapter, you will recall nurses' response to Brittany's apparently overbearing father in the ward, with his "watching everything we do" to his "precious princess". With new understanding, I could now appreciate that he is well initiated into the binary of life and death, and thus his motivation for care may be quite different from those medical carers who join in the routine. Drawing upon insight gained from this research project, I can understand that he is bound with his daughter in this daily life and death encounter.

The initial observers were right in one aspect. Brittany is not really a princess, because once she sleeps the sleep of death, no amount of kisses from a handsome prince will restore her to 'live happily ever after'.

While children with CF continue to live an abridged edition of their story, the opportunity exists for those caring for them and their parents to not only appreciate their predicament, but to help them to construct a tale that can accentuate as much of life as possible, while distancing the opposing partner in their binary. Because we all know how the story ends.

## Epilogue: putting possibilities into practice

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Where has this research trail led me? I began with a request from nurses in practice. Have I answered it for them? In phenomenology there is no answer, no findings as such. Rather, drawing on Fitzgerald's (1995) work, to offer a conclusion to an interpretive phenomenological study would be a strange concept, interpretations being always susceptible to further interpretation. My aim in this study has not been a generalised set of findings, but to present a potent portrayal of the phenomenon, aware of the transient nature of understanding. Do not imagine that you have missed 'the punch-line, the latest information, or the big news' (van Manen 1990:13). A poem is not suited to being summarised into an outcome, it being the end result. So a phenomenological study does not lend itself to a concluding summary (p.13).

I have presented a rich description of living with CF that can inform nursing - in practice, education and research. Such understanding has the potential to influence the provision of care, appropriately encompassing all the contexts in which children with CF and their parents live.

### Practice potential

What might be the impact of this research upon practice? The sub-themes of fright, fear, fight, flight, familiarity, form, future and philosophy have emerged through the data gathered from the participants in their 'other world'. However, the life and death binary in which these parents and children are bound would seem to be the essence of that life in whatever situation it is enacted, including the various arenas in which nursing care is given.

Colleagues with fresh understandings have the potential to deliver enhanced care that is appropriate to the experience as now understood, rather than presumed to be. By recognising participants' reactions of fright - initial on the part of the parents, while punctuating episodes lead to realisation on the part of children - nurses can appreciate that both are coping with the ensuing fear.

Living with CF necessitates a fight, one in which nurses can engage. They can do so more effectively when understanding that they are caring for a child who is coming to the gradual awareness that it is a fight for life. Thus it is necessary to create positive hospital experiences because these children will be returning. There will be more like Grace, whose terror in the x-ray process was reduced by a simple change of operator. Such incidences could be diffused by communication and advocacy on the part of nurses, alleviating trauma not only for the child, but also for distressed parents like Cathy and Brad, who had to negotiate on their child's behalf.

Parents need allies in their particular fight, central to which is the treatment of their child's form. They assume that medical carers will display an awareness of scrupulous techniques and prevention of cross-infection. With such insight, nurses can be sensitive to parents and children who are watching their every move. Kate and Pete were noting hospital routine in order to verify their own. Glaring discrepancies made them resolve: "There's no way that child's going back to hospital." These parents reflected nurses' roles in their account by painting nurses into the background of busyness in the hospital setting. That nurses were generally subliminal in participants' contributions highlights a need for nurses to not only relate in redefined ways with them, but to overtly take part in their fight against CF.

That most parents highlighted the need for appropriate and accessible services is an appeal that should not be overlooked. It signifies both a deficit and an opportunity for nurses to be involved apart from an acute care setting. My colleagues' initial comments that they "only see them when they're acute" carries with it the desire and potential to also participate in their lives at other times and in other settings, such as community-based care. Opportunities include follow-up and home-based support, liaison with the multidisciplinary team and between larger centres, and coordination of statewide services. Care would be facilitated by the promotion of designated CF nursing positions.

Considerations for practice should not be limited to the paediatric domain. Now that people with CF are living well into adulthood (Robinson 2001:237), nurses in adult settings will find themselves asking similar questions to the ones posed by those in paediatrics.

## **Education and equipping**

While nurses reflecting upon their practice do realise new queries, there is also place for pre-emptive education. This potentially alleviates both tension with the unknown on nurses' part, and stress at being misunderstood on that of those with CF, and their parents.

Nurses need to be furnished with information and treatment strategies that are current, thus avoiding the supply of outmoded or erroneous facts that have been reported in this study. Particularly in a region with a noted high rate of CF, as is the case where this study has been executed, it would seem appropriate that knowledge of the disease be featured in nursing education. While initial learning about CF can occur by way of undergraduate curricula, there is obviously a place for ongoing learning. This is evidenced by participants who perceived medical carers' knowledge to have paused with the last person with CF they had encountered, however long ago that may have been.

Continuing research into CF initiates changes in treatment and prognosis. Hence there is an imperative for ongoing professional development. Education that is not simply skills focused, but balanced with psychological and sociological expertise, would enable nurses to deliver the most up-to-date care, and render them competence in dealing with the specific needs of those living with CF. Nurses so engaged are dealing with a person with a terminal illness - a child who comes to a realisation that they will die prematurely, and parents who know they will lose their offspring.

That nurses originally asked the question that led to my inquiry demonstrates their apprehension that they are not fully aware of the patients' perspectives. Inclusion of CF into undergraduate and suitable postgraduate programmes, such as those in paediatrics or critical care, would not only furnish practitioners with knowledge that is disease-specific, but also render understanding that can enhance their care of people with other chronic illnesses, and conditions in which life and death scenarios are confronted.

To confine such education to paediatrics courses is no longer appropriate. Because of the increasing progression of those with CF to adulthood, future care will involve

nurses in adult units, both in increased palliative care, and acute surgical nursing because of transplantation.

I was unaware just how unsatisfactory the delivery of information is perceived to be by those living with CF. Some participants felt it was piecemeal, while for others, it was like an overwhelming avalanche. Obviously there is not going to be a 'one-size-fits-all' method to satisfy each individual, with children's requirements differing from their parents. Rather, as with medications, it is a case of right person, right amount, right mode and right time. This occurs most effectively within a relational exchange facilitated by practitioners equipped with communication and counselling skills that enhance their natural empathetic approach.

### **Further investigation**

The researcher is often left with a sense of having shared experience and issues that not only need further explication, but are also attended by a myriad of further ones that have been raised for investigation. Such is the ongoing nature of lived experience that new matters for consideration arise.

Focus on efficacious information provision is a glaring need considering the weight placed upon its procurement by participants in this project. Further studies are needed to examine the appropriate acquisition of current facts, and how to disseminate them to those with CF, to practitioners, and to the public. Follow-up projects would review the process of handling information and any materials used, asking whether these have been effectively received.

Research that appraises nurses' education and their preparedness to care for patients with CF would alleviate uncertainty such as that expressed by my practice colleagues. Likewise, a study that enquired of schoolteachers regarding their perceived role in the care of an affected child in their class would be particularly valuable in identifying appropriate education for these professionals. Parents in this study have placed certain expectations upon teachers, who influence not only the physical health but also the coping and normalising strategies of children with CF. Nurses would be well placed to contribute in an educative role in the school setting, relieving parents of this imperative, and teachers of their uncertainty.



The need for statewide, coordinated services was not some half-hearted thought on the part of participants, but expressed in sentiments like Pete's: "There was no centralised care for someone getting the right treatment, the right advice." Is such care the panacea? Or are there alternatives that have not yet been formulated? Of what should services consist? Where would they be best situated?

The new insights generated by my research project have confirmed some studies (Admi 1995; Bluebond-Langer 1996; Lowton 2004), and realised further potential in others. Various authors suggest further research possibilities as a result of their work. Lowton (2004:169) notes the lack of documentation regarding how adults with CF deal with the issue of disclosing their possible infertility and shortened lifespan to potential partners. These topics arose during my discussion with Bob, as he conveyed his dilemma regarding his hoped-for wife and family, and the candid conversation we had around this aspect of his attaining adulthood. Not only disclosure of his having CF to a future partner, but the ascertaining of her carrier status, were matters that he talked about in depth, and were subject to much conjecture.

Potential areas for research with adults who have CF are extensive, particularly as major life and death events are being confronted in this life stage. How are they faring? What choices have they made regarding careers, partners and families? What have been their responses to the latest reproductive technology? What implications for nursing care do such options engender?

Following her study with nurses caring for young people with CF, Tippl (1995:123) proposes an additional study that considers the perceptions that adolescents and their families have of their relationships with nurses, and their care expectations. Having explored the experience of adolescents and their parents from my research perspective, this is a complementary area that has potential to further enhance nursing practice, and is an area I would be keen to investigate further.

Areas to be explored include the experience of siblings of children with CF - a distinct group with particular issues that punctuate their life experience. They warrant a study of their own.

What might be the experience of parents whose child has died from CF? I met several such people, and I was struck by two thoughts. They no longer have corporeal relationship with their children nor the responsibility of their form, and the daily fear has been fulfilled. They are now negotiating the future they had conjectured, and about which they had speculated. How are parents supported through their child's death and its aftermath? What queries might nurses have about *them*?

It would be fascinating to talk with my participants again, several years hence. A longitudinal study would provide yet another view of children growing up with a condition that has an evolving disease trajectory. For those children who have attained adulthood, where might their plans have taken them? Who has Bob married? How far is Tim down his "set of things ... to do"? Has Hannah taken the trips she envisaged? Does Brooke still want to "fast-forward" her life? Is Grace still older than Bronte? Toby would probably be able to articulate his physiotherapy routine, while Mark would be able to speak on his own behalf. As for Ian and Max, would they now choose to tell their side of their story, albeit still a matter of life and death?

### **A worn trail**

I began this project with the stated desire to make patent the trail I would follow. I have detailed the story of my journey as researcher, and interwoven it with the stories of the children and parents who have collaborated in this endeavour. My intent has been to render as potent an understanding of the research context as my words can convey, thus rendering this work credibility (Koch 1998:1188).

To demonstrate dependability (Guba & Lincoln 1989:242), I have enumerated the steps taken from the initial input from my practice colleagues, through the process of gaining ethics approval, to contacting and visiting participants, and the approach to analysis I have taken to deliver a faithful exposé of the phenomenon of living with CF. By so doing, another investigator could proceed along a similar track.

And what of transferability? While the burden of proof for claimed generalisability lies with the inquirer, that for transferability is with the receiver, write Guba and Lincoln (1989:241). While this project has been conducted in a specific context, I have received affirmative feedback when presenting highlights from it in diverse

settings. Those involving nurses have included undergraduate and postgraduate learning sessions, and both national and international conferences. I noted the intermittent 'phenomenological nods' that were the response of listeners. Their responses resonated with that of not only the participants, but also with the nurses who originally confessed a lack of understanding, and with me, as the one who had the privilege of seeking it out.

Koch (1998:1184) emphasises the centrality that reflexivity should occupy in the research process. This has been an integral component in my execution of the study. In retrospect, I am satisfied that the research trail is dependable, credible and transferable. Would I have chosen a different route? My adopting a phenomenological perspective and utilising van Manen's (1990:101) existentials of time, body, space and relationship has rendered valuable insight, and has been particularly fitting for understanding the lifeworld affected by CF.

### **Within the limits**

While every researcher sets out with the goal of producing a work that is rigorous in methodology and profound in outcomes, there are limitations, both anticipated and unpredictable, that will moderate those intentions. This study is restrained by its situation in an explicit context - that of an island setting, with participants sharing the commonalties of race and language. Considering the nature of inheritance of the CF gene, however, a cohort of people with this disease will tend to be of Celtic origins.

Phenomenology presents specific limitations. As with any methodology, it delivers one particular view - in this case, of the individuals' experience. Other methodologies would have highlighted other aspects. An ethnographic approach, for example, would have conveyed a cultural aspect, while a discourse analysis would have examined the language with which participants frame their lifeworld. Thus, while I have considered the experience of living with CF, there are other facets of that life that are not included within the methodological framework I have employed.

A practical limitation has been the constraints imposed by method and ethics. It would have been ideal to initially meet participants with tape-recorder, felt pens and paper in hand, in order to capture the purely pre-reflective experience that several

immediately recalled when I first introduced the research question to them. I had to quickly change the subject, and invite them to hold their thoughts until the subsequent interview time that ethical and procedural constraints dictated.

Particularly in a project of this nature, that explores human experience, the process is influenced by the subjectivity that is inherent in humanness. Data collection is moderated by the participants' recall of retrospective life experience, their ability to articulate it, and the researcher's descriptive skills. These are also positive attributes, as it is by means of the unstructured and unforeseeable qualities of person-to-person research that a resultant depth of insight is achieved, one that may remain unplumbed by more detached, structured enquiry.

So it was that I set out as researcher, I was attended by my other roles and biases, particularly that of nurse, which renders me an insider's acquaintance. Is this a limitation, or does it mean that by my being *au fait* with people encountering disease, finer points of experience and care are enhanced by my orientation? Conversely, as this project has shown, nurses may be well-versed in the expert knowledge to administer appropriate treatment, but feel uninitiated into the lifeworld of the people who are the beneficiaries of it.

I recall my experience as an Honours investigator. Having met the participants in an acute paediatric setting, I exchanged my clinical hat for that of researcher, and visited them with that demeanour. This is effective up to a point, but even those in this study whom I did not know previously, were acquainted with the fact that I was a nurse, and that I had come "from the hospital". This deduction was the result of the ethical and gate keeping restraints that required me to be introduced to them at the outpatient's clinic. This could have hindered some participants from sharing openly, a fact that crossed my mind as some shrank from the tape recorder. However, even those who considered they did not really have much to tell soon warmed to the opportunity when encouraged to talk anonymously, their words flowing freely once they began.

This identity of me as half nurse, plus the fact that these people are used to being quizzed on their medical progress, meant that some assumed I was wanting more of the same medico-scientific data, exemplified by Liz's: "She's been well ... We're

probably not what you need.” Likewise Tim’s transplant tale was initially medically focused, because he no doubt wanted to tell me such detail, and assumed that would interest me. It was certainly enthralling, but so too was the experience of Tim, the man, into which he eventually delved.

My constant tension while working with the data has been to develop as credible an interpretation as one human being can by looking into the lifeworld of another. I have done so, wearing the 3-D glasses not only of nurse, but of parent, plus a myriad of other filters I have acquired over the years. Were I to take another look at a subsequent time, possibly new shades of meaning would appear, and enhance my current description of the phenomenon.

So some limitations are conversely strengths because they reflect the humanness of both researcher and participant. You as reader are completing the process by assimilating the work through your perceptions, adding your humanness to the equation.

### **In the end**

I set out to explicate: “What is the experience of living with cystic fibrosis?”, and this project is now completed. I cease writing. You close the book, and go on your way. What have you gleaned? What further understanding of a life lived with CF? Has this stimulated insight into new possibilities for care? Or are you relieved, perhaps, that it is a story about others and not you?

# Appendix 1

[ADULT AND CHILD]

## Invitation:

### To participate in a research project:

**‘Towards an understanding of living with cystic fibrosis: the experience of children, adolescents, young adults and their families.’**

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My name is Melanie Jessup and I am a Registered Nurse in paediatrics. I am undertaking this project as a requirement for a PhD degree.

Here are the answers to some of the questions you may have about the study:

#### **1) What is the purpose of this study?**

The purpose of this study is to gain a better understanding of your experience of living with cystic fibrosis, leading to the improved planning and provision of care.

#### **2) What would I be asked to do if I were to participate in the study?**

I will phone you within the coming week to see whether you and your child would like to participate. You are under no obligation to do so. I will answer any questions you have, and will make a time to visit you at home or a suitable venue, for about an hour or so. During that visit, I will ask you to sign a consent form for you and your child. We will then have a discussion about your experience of having a child with cystic fibrosis, followed by an informal chat with your child, with your permission.

#### **3) What information would be recorded for this study?**

I'll have a tape recorder going while we talk. This is because the information gained during the interviews is extremely valuable, and recording the interview and then typing it out or 'transcribing' it is the best way to make sure that your experiences are recorded accurately. You can have access to the transcripts should you wish.

**4) Who will be told about any information that I give?**

At all times your confidentiality will be maintained by using pseudonyms (false names) in any written record of details. Any identifying details will be altered to conceal your identity, and that of any individuals you mention.

**5) What will be done with the information that I give?**

Information gathered in this study will be used in a PhD thesis and articles reporting the findings.

**6) Do I have to participate?**

No. There is no obligation at all to participate.

**7) Can I change my mind if I decide to participate?**

You will be most certainly free to choose to not talk about anything you don't want to, and to finish our conversation at anytime. Likewise, your child will in no way be coerced to continue participating if they desire not to. You are also free to withdraw from the study at any time without any effect on your child's medical care now or in the future. Your contribution is entirely on the basis that you are keen to make it.

**8) What if I feel that I would like to talk to someone about any thoughts, feelings or memories that the interview might raise?**

If you would like a supportive listener at any time after the interview, Janet Anand at the social work department can be contacted on 63487247.

**9) What if I have any other questions about the study?**

If you have any questions about the study, you are welcome to contact:

Dr Camillus Parkinson – Chief Investigator  
Tasmanian School of Nursing  
Phone: 62264895

Melanie Jessup – Associate Researcher  
Tasmanian School of Nursing  
Phone: 63243318

Associate Professor Carey Denholm – Associate  
Graduate Dean of Studies  
Phone - 62267127

Should you have any concerns of an ethical nature, you may contact:

Dr Janet Vial

Chairperson

University Ethics Committee

Phone: (03) 62264842

Chris Hooper

Executive Officer

University Ethics Committee

Phone: 62262763

**9) Is this study being undertaken with permission?**

The Launceston General Hospital and the University of Tasmania have approved this project.

I look forward to talking with you, and thank you in advance for the valuable contribution you will be able to make to it.

Melanie Jessup

Associate Researcher



[ADULT]

## **Invitation:**

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#### **2) What would I be asked to do if I were to participate in the study?**

I will phone you within the coming week to see whether you would like to participate. You are under no obligation to do so. I will answer any questions you have, and will make a time to visit you at home or a suitable venue, for about an hour or so. During that visit, I will ask you to sign a consent form. We will then have a discussion about your experience of cystic fibrosis.

#### **3) What information would be recorded for this study?**

I'll have a tape recorder going while we talk. This is because the information gained during the interviews is extremely valuable, and recording the interview and then typing it out or 'transcribing' it is the best way to make sure that your experiences are recorded accurately. You can have access to the transcripts should you wish.

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Melanie Jessup

Associate Researcher

## Appendix 2

### STATEMENT OF INFORMED CONSENT - ADULT

Project Title: 'Towards an understanding of living with cystic fibrosis: the experience of children, adolescents, young adults and their families.'

Chief Investigator: Dr Camillus Parkinson

Associate Investigators: - Melanie Jessup  
- Associate Professor Carey Denholm

### STATEMENT BY THE PARTICIPANT

- I have read and understood the letter of information regarding this study.
- The nature and possible effects have been explained to me.
- I understand that I will be professionally supported in the event that any anxieties should arise.
- I understand that the study involves participating in a one hour conversation
- I understand that all information will remain confidential.  
Any questions that I have asked have been answered to my satisfaction.
- I agree to participate in this investigation and understand that I may withdraw at any time without affecting my care now or in the future.
- I agree that the research data gathered for the study may be published provided that I cannot be identified as a subject.

NAME OF PARTICIPANT \_\_\_\_\_  
SIGNATURE OF PARTICIPANT \_\_\_\_\_ DATE \_\_\_\_\_

### STATEMENT BY INVESTIGATOR

- I have explained this project and the implications of participation in it to this participant.
- I believe that the consent is informed and that they understand the implications of participation.

NAME OF INVESTIGATOR \_\_\_\_\_  
SIGNATURE OF  
INVESTIGATOR \_\_\_\_\_ DATE \_\_\_\_\_

## STATEMENT OF INFORMED CONSENT - CHILD

Project Title: 'Towards an understanding of living with cystic fibrosis: the experience of children, adolescents, young adults and their families.'

Chief Investigator: Dr Camillus Parkinson

Associate Investigators: - Melanie Jessup  
- Associate Professor Carey Denholm

## STATEMENT BY PARENTS

- We have read and understood the letter of information regarding this study.
- The nature and possible effects have been explained to us.
- We understand that our child will be professionally supported in the event that any anxieties should arise.
- We understand that the study involves our child participating in an informal conversation, and that all information will remain confidential.
- Any questions that we have asked have been answered to our satisfaction.
- We give consent for our child \_\_\_\_\_ to participate in this investigation.
- We understand that they may withdraw at any time without affecting their care now or in the future.
- We agree that the research data gathered for the study may be published provided that our child cannot be identified as a subject.

NAME OF PARENT \_\_\_\_\_  
SIGNATURE OF PARENT \_\_\_\_\_ DATE \_\_\_\_\_

NAME OF PARENT \_\_\_\_\_  
SIGNATURE OF PARENT \_\_\_\_\_ DATE \_\_\_\_\_

## STATEMENT BY INVESTIGATOR

- I have explained this project and the implications of participation in it to these participants.
- I believe that the consent is informed and that they understand the implications of participation.

NAME OF INVESTIGATOR \_\_\_\_\_  
SIGNATURE OF INVESTIGATOR \_\_\_\_\_ DATE \_\_\_\_\_

## References

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*A Current Affair*, screened Channel 9 TV, April 2, 2003.

Admi, H. 1993, 'Growing up with a chronic disease: Life histories of adolescents and young adults with cystic fibrosis', *Dissertation Abstracts International, University of Pennsylvania*, 54: 1327-1328.

Admi, H. 1995, "'Nothing to hide and nothing to advertise": managing disease-related information', *Western Journal of Nursing Research*, 17(5): 484-501.

Al-Aloul, M., Crawley, J., Winstanley, C., Hart, C. A., Ledson, M. J. & Walshaw, M. J. 2004, 'Increased morbidity associated with chronic infection by an epidemic *Pseudomonas Aeruginosa* strain in CF patient', *Thorax*, 59:334-336.

Allan, J. L. & Phelan, P. D. 1985, 'Incidence of cystic fibrosis in ethnic Italians and Greeks and in Australians of predominantly British origin', *Acta Paediatrics*, 74(2): 286-289.

Andersen, D. H. 1938, 'Cystic fibrosis of the pancreas and its relation to celiac disease', *American Journal of Diseases of Children*, 56: 344-399.

Anderson, K. L. & Burckhardt, C. S. 1999, 'Conceptualization and measurement of quality of life as an outcome variable for health care intervention and research', *Journal of Advanced Nursing*, 29(2): 298-306.

Arumugam, R., Reid, B., Fan, L. L., Braverman, R. M. & Scheimann, A. O. 1999, 'Cystic fibrosis presenting as massive hepatomegaly', *Clinical Pediatrics*, 38(12): 731-3.

Australasian CF Data Registry 2000, *Cystic Fibrosis in Australia and New Zealand 2000*, Cystic Fibrosis Australia, North Ryde, NSW, Australia.

*Australian Story*, screened ABC TV, July 7, 2001.

Axworthy, D., Brock, D. J. H., Bobrow, M. & Marteau, T. M. 1996, 'Psychological impact of population-based carrier testing for cystic fibrosis: 3-year follow-up', *The Lancet*, 347(9013): 1443.

Baily, C. 1998, 'Second wind,' *Scholastic Scope*, 47(3): 14-17.

Balfour-Lynn, M., Martin, I., Whitehead, B. F. & Rees, P. G. 1997, 'Heart-lung transplantation for patients under 10 with cystic fibrosis', *Archives of Disease in Childhood*, 76(1): 38-40.

Bannon, M. J. & Ross, E. M. 1998, 'Administration of medicines in school: who is responsible?', *British Medical Journal*, 316: 1591-1593.

Barone, T. 2001, *Touching Eternity: The Enduring Outcomes of Teaching*, Teachers College Press, New York.

Baroni, M. A., Anderson, Y. E. & Mischler, E. 1997, 'Cystic fibrosis newborn screening: impact of early screening results on parenting stress', *Pediatric Nursing*, 23(2): 143-150.

Barthes, R. 1986, *The Rustle of Language*, Hill and Wang, New York.

Bartholomew, L. K., Czyzewski, D. I., Swank, P. R., McCormick, L. & Parcel, G. S. 2000, 'Maximizing the impact of the cystic fibrosis family education program: factors related to program diffusion', *Family & Community Health*, 22(4): 27-47.

Baumann, U., Stocklossa, C., Greiner, W., Von Der Schulenburg, J. M. G. & Von Der Hardt, H. 2003, 'Cost of care and clinical condition in paediatric cystic fibrosis patients', *Journal of Cystic Fibrosis*, 2(2): 84-90.

Beker, L., Russek-Cohen, E. & Fink, R. 2001, 'Stature as a prognostic factor in cystic fibrosis survival', *Journal of the American Dietetic Association*, April 2001: 438-442.

- Bennett, R. L. 2000, 'Pedigree parables', *Clinical Genetics*, 58: 241-249.
- Blest, N. 2000, Survival analysis of cystic fibrosis in Australia 1968-1998, Honours thesis, University of Tasmania.
- Bluebond-Langer, M. 1996, *In the Shadow of Illness: Parents and Siblings of the Chronically Ill Child*, Princeton University Press, Princeton, New Jersey.
- Boas, S. R., Fulton, J. A., Koehler, A. N. & Orenstein, D. M. 1998, 'Nutrition and pulmonary function predictors of delayed puberty in adolescent males with cystic fibrosis', *Clinical Pediatrics*, 37(9): 573-576.
- Bolyard, D. R. 2001, 'Sexuality and Cystic Fibrosis', *The Journal of Maternal Clinical Nursing*, 26(1): 39-41.
- Boughton, M. A. 2002, 'Premature menopause: multiple disruptions between the woman's biological body experience and her lived body', *Journal of Advanced Nursing*, 37(5): 423-430.
- Braekeleer, M. 1994, 'Prenatal screening for cystic fibrosis,' *The Lancet*, 343(January 15): 172-173.
- Britto, M. T., Garrett, M., Dugliss, A. J. & Daeschmer Jr., C. W. 1998, 'Risky behaviour in teens with cystic fibrosis or sickle cell disease: a mulitcenter approach', *Pediatrics*, 101(2): 250-256.
- Brock, D. J., Gilfillan, A. & Holloway, S. 1998, 'The incidence of cystic fibrosis in Scotland calculated from heterozygote frequencies,' *Clinical Genetics*, 53(1): 47-49.
- Burton, L. 1975, *The Family Life of Sick Children*, Routledge & Kegan Paul Ltd., London.
- Caelli, K. 2000, 'The changing face of phenomenological research: traditional and American phenomenology in nursing', *Qualitative Health Research*, 10(3): 366-377.



- Campbell, A. K. 2003 'Save those molecules! Molecular biodiversity and life', *Journal of Applied Ecology*, 40:193.
- Canda, E. R. 2001, 'Transcending through disability and death: transpersonal themes in living with cystic fibrosis', *Social Thought*, 20(1/2): 109-134.
- Carew, L. D. 2001, 'The adolescent with cystic fibrosis: a psychosocial perspective', *Southern African Journal of Child and Adolescent Mental Health*, 13(1): 23-29.
- Carr, D. 1974, *Phenomenology and the Problem of History: A Study of Husserl's Transcendental Philosophy*, Northwestern University Press, Evanston, USA.
- Chambers, J. 2002, 'Cystic fibrosis in the former Soviet Union', *International Integrated Health Association*, [Online, accessed September 21, 2002], <http://www.iacfa.org/newsletter/n199/n199.htm>.
- Chapman, E. 2002, 'The social and ethical implications of changing medical technologies: the views of people living with-genetic conditions', *Journal of Health Psychology*, 7(2): 195-206.
- Chernoff, R. G., Ireys, H. T., De Vet, K. A. & Kim, Y. J. 2002, 'A randomised controlled trial of a community-based support program for families of children with chronic illness: pediatric outcomes', *Archives of Pediatrics & Adolescent Medicine*, 156(6): 533.
- Chisholm, C. 2003, 'Fight of a lifetime', *The Australian Women's Weekly*, April, p. 76.
- Christian B., D'Auria, J. & Moore, C. 1999, 'Playing for time: adolescent perspectives of lung transplantation for cystic fibrosis', *Journal of Pediatric Health Care*, 13: 120-125.

- Cleary, J. Gray, O. P., Hall, D. J., Rowlandson, P.H., Sainsbury, C. P. & Davies, M. 1986, 'Parental involvement in the lives of children in hospital', *Archives of Disease in Childhood*, 61: 779-787.
- Collins, C. E., MacDonald-Wicks, L., Rowe, S., O'Loughlin, E. V. & Henry, R. L. 1999, 'Normal growth in cystic fibrosis associated with a specialised centre', *Archives of Disease in Childhood*, 81(3): 241-246.
- Concise Oxford Dictionary*, 1979, ed. J. B. Sykes, Oxford University Press, Oxford.
- Conley, H. & Kubusch, S. M. 1997, 'The relationship of self-perception of illness and compliance with health care regimens', *Journal of Advanced Nursing*, 25: 548-553.
- Conway, S. 1998, 'Recombinant human DNase (rhDNase) in cystic fibrosis: is it cost effective?', *Archives of Disease in Childhood*, 77(1): 1-3.
- Corey, M. 2001, 'Modelling survival in cystic fibrosis,' *Thorax* (56): 743-745.
- Cornacchia, M., Zenorini, A., Perobelli, S., Zanolla, L., Mastella, G. & Braggion, C. 2001, 'Prevalence of urinary incontinence in women with cystic fibrosis', *British Journal of Urology International*, 88: 44-48.
- Cox, S. M. & McKellin, W. 1999, "'There's this thing in our family": predictive testing and the construction of risk for Huntington Disease', *Sociology of Health & Illness*, 21(5): 622-646.
- Coyne, I. 1997, 'Chronic illness: the importance of support for families caring for a child with cystic fibrosis', *Journal of Clinical Nursing*, 6: 121-129.
- Crisp, J., Ungerer, J. A. & Goodnow, J. J. 1996, 'The impact of experience on children's understanding of illness,' *Journal of Paediatric Psychology*, 21(1): 57-72.
- Crosier, J. & Wise, L. C. 2001, 'Coming of age', *Nursing Management*, 32(11): 30-31.

- Crotty, M. 1996, *Phenomenology and Nursing Research*, Churchill Livingstone, Melbourne.
- Crotty, M. 1997, 'Tradition and culture in Heidegger's Being and Time', *Nursing Inquiry*, 4: 88-98.
- Cunningham, S. & Marshall, T. 1998, 'Influence of five years of antenatal screening on the paediatric cystic fibrosis population in one region', *Archives of Disease in Childhood*, 78: 345-348.
- Curtis, B. 1978, 'Introduction', in *Phenomenology and Education: Self-consciousness and its Development*, Curtis, B. & Mays, M. eds., Methuen & Co. Ltd., London, pp. ix-xxvi.
- Curtis, J. R., Burke, W., Kassner, A.W. & Aitken, M. L. 1997, 'Absence of health insurance is associated with decreased life expectancy in patients with cystic fibrosis', *American Journal of Critical Care*, 155: 1921-1924.
- Czechmeister, C. A. 1994, 'Metaphor in illness and nursing: a two-edged sword. A discussion of the social use of metaphor in everyday language, and implications of nursing and nursing education', *Journal of Advanced Nursing* 19(6): 1226-1233.
- Darbyshire, P. 1992, Parenting in public: a study of the experiences of parents who live-in with their hospitalised child, and of their relationships with paediatric nurses, PhD thesis, University of Edinburgh.
- Darbyshire, P. 1994, 'Understanding caring through arts and humanities: a medical/nursing humanities approach to promoting alternative experiences of thinking and learning', *Journal of Advanced Nursing*, 19: 856-863.
- Darbyshire, P., Diekelmann, J. & Diekelmann, N. 1998, 'Reading Heidegger and interpretive phenomenology: a response to the work of Michael Crotty', *Nursing Inquiry*, 6:17-25.

- Darbyshire, P., Oster, C. & Carrig, H. 2001, 'Children of parent(s) who have a gambling problem: a review of the literature and commentary on research approaches', *Health & Social Care in the Community*, 9(4): 185-193.
- Davies, J., Trindale, M-T., Wallis, C., Rosenthal, M., Crawford, O. & Bush, A. 1997, 'Retrospective review of the effects of rhDNase in children with cystic fibrosis', *Pediatric Pulmonary* (23): 243-248.
- Dayton, L. 2004, 'Embryo research starts now', *The Weekend Australian*, March 17-18, p. 3.
- De Braekeleer, M. 1994, 'Prenatal screening for cystic fibrosis', *The Lancet*, 343:172.
- De Jong, W., Kaptein, A. A., Van der Schans, C. P., Mannes, G. P. M., Van Aalderen, W. M. C., Grevink, R. G. & Koeter, G. H. 1997, 'Quality of life in patients with cystic fibrosis', *Pediatric Pulmonology*, 23: 95-100.
- Dickinson-Herbst, D. 2001, 'Cystic fibrosis and lung transplantation: ethical concerns', *Pediatric Nursing*, 27(1): 87-89.
- Dickinson, P., Smith, S. N., Webb, S., Kilanowski, F. M., Campbell, I. J., Taylor, M. S., Porteous, D. J., Willemsen, R., de Jonge, H. R., Farley, R., Alton, E. W. & Dorin, J. R. 2002, 'The severe G480C cystic fibrosis mutation, when replicated in the mouse, demonstrates mistrafficking, normal survival and organ-specific bioelectrics', *Human Molecular Genetics*, 11(3): 243-251.
- Dimensions*, screened ABC TV, October 31, 2002.
- Dodge, J. A. 1998a, 'Commentary: management in paediatric and adult cystic fibrosis centres improves clinical outcome,' *British Medical Journal*, 316(7147): 1775.
- Dodge, J. A. 1998b, 'Neonatal screening for cystic fibrosis', *British Medical Journal*, 317(7155): 411.

- Dodge, J. A., Morison, S., Lewis, P. A., Coles, E. C., Geddes, D., Russell, G., Littlewood, J. M. & Scott, M. T. 1997, 'Incidence, population, and survival of cystic fibrosis in the UK, 1968-95', *Archives of Disease in Childhood*, 77: 493-496.
- Doull, I. J. M. 2001, 'Recent Advances in cystic fibrosis', *Archives of Disease in Childhood*, 85: 62-66.
- Doull, I. J. M., Ryley, H. C., Weller, P. & Goodchild, M. C. 2001, 'Cystic fibrosis related deaths in infancy and the effect of newborn screening', *Pediatric Pulmonology*, 31: 363-366.
- Dreyfus, H. 2002, 'Heidegger, Martin', *Microsoft Encarta Online Encyclopedia 2002*, [Online, accessed July 28, 2002] <http://encarta.msn.com>.
- Dudding, T., Wilcken, B., Burgess, B., Hambly, J. & Turner, G. 2000, 'Reproductive decisions after neonatal screening identifies cystic fibrosis', *Archives of Disease in Childhood, Fetal Neonatal Edition*, 82: F124-F127.
- Durst, C. L., Horn, M. V., MacLaughlin, E. F., Bowman, C. M., Starnes, V. A. & Woo, M. S. 2001, 'Psychosocial responses of adolescent cystic fibrosis patients to lung transplantation', *Pediatric Transplantation*, 5: 27-31.
- Edenborough, F. P. 2001, 'Women with cystic fibrosis and their potential for reproduction', *Thorax*, 56: 649-655.
- Edenborough, F. P. 2002, 'Pregnancy in women with cystic fibrosis', *Acta Obstetrica et Gynecologica Scandinavica*, 81: 689-692.
- Edmestone, L. 2003, 'Triple transplant first gives hope to dying man', *The Courier Mail* (Brisbane), August 5, p. 1.
- Eiser, C. 1989, 'Children's concepts of illness: towards an alternative to the "stage" approach', *Psychology and Health*, 3: 93-101.

Eiser, C. 1993, *Growing Up with a Chronic Disease: The Impact on Children and Their Families*, Jessica Kingsley Publishers, London.

Eiser, C. 2003, 'What can we learn from other illnesses?' *Journal of Cystic Fibrosis*, 2: 58-60.

Eiser, C., Mohay, H. & Morse, R. 2000, 'The measurement of quality of life in young children', *Child: Care, Health and Development*, 26(5): 401-414.

Eiser, C. & Morse, R. 2001, 'A review of measures of quality of life for children with chronic illness', *Archives of Disease in Childhood*, 84: 205-211.

Elborn, S. 1998, 'The management of young adults with cystic fibrosis: "genes, jeans and genies" ', *Disability and Rehabilitation*, 20(6/7): 217-225.

Elborn J. S., Shale, D.J. & Britton J. R. 1991, 'Cystic fibrosis: current survival and population estimate to the year 2000,' *Thorax*, 46: 881-885.

Emad, P. 1993, 'Thinking more deeply into the question of translation: essential translation and the unfolding of language', in *Reading Heidegger: Commemorations*, ed. John Sallis, Indiana Press, Bloomington and Indianapolis, p. 323-340.

Embree, L. 2000, 'What is phenomenology?', *Centre for Advanced Research in Phenomenology*, [Online, accessed July 28, 2002]  
<http://www.phenomenologycenter.org/phenom.htm>.

Emery, J. 2001, 'Is informed choice in genetic testing a different breed of informed decision-making ?', *Health Expectations*, 4: 81-86.

Fair, A., Griffiths, K. & Osman, L. M. 2000, 'Attitudes to fertility issues among adults with cystic fibrosis in Scotland', *Thorax*, 55: 672-677.

- Farrell, P. M., Kosorok, M. R., Rock, M. J. & Laxova, A. 2001, 'Early diagnosis of cystic fibrosis through neonatal screening prevents severe malnutrition and improves long-term growth', *Pediatrics*, 107(1): 1-13.
- Ferrin, M., Happ, M. B. & Kagan, S. H. 2001, 'Palliative care and lung transplantation: conflict or continuum?', *American Journal of Nursing*, 101(2): 61-66.
- Fisher, H. R. 2001, 'The needs of parents with chronically sick children: a literature review', *Journal of Advanced Nursing*, 36(4): 600-607.
- Fitzgerald, M. 1995, *The Experience of Chronic Illness in Rural Australia*, PhD thesis, University of New England, Armidale, NSW, Australia.
- FitzSimmons, S. 1993, 'The changing epidemiology of cystic fibrosis', *Journal of Pediatrics*, 122(1): 1-9.
- Foster, C. L., Bryon, M. & Eiser, C. 1997, 'Correlates of well-being in mothers of children and adolescents with cystic fibrosis', *Child: Care, Health and Development*, 24(1): 41-56.
- Foster, C., Eiser, C., Oades, P., Sheldon, C., Tripp, J., Goldman, P., Rice, S. & Trott, J. 2001, 'Treatment demands and differential treatment of patients with cystic fibrosis and their siblings: patient, parent and sibling accounts', *Child: Care, Health and Development*, 27(4): 349-364.
- Fox, A. 2002, 'Physicians as barriers to successful transitional care', *International Journal of Adolescent Medicine & Health*, 14(1): 3-7.
- Fraser, A. 2003, 'Transplant a success', *The Weekend Australian*, August 9-10, p. 4.
- Frossard, P. M., Lestringant, G., Girodon, E., Goossens, M. & Dawson, K. P. 1999, 'Determination of the prevalence of cystic fibrosis in the United Arab Emirates by genetic carrier screening', *Clinical Genetics*, 55: 496-497.

Gadamer, H. G. 1975, *Truth and Method*, eds. Barden, G. & Cumming, J., Sheed and Ward, London.

Gadamer, H. G. 1996, *The Enigma of Health*, Stanford University Press, California.

Garwick, A. W., Patterson, J. M., Bennett, F. C. & Blum, R. W. 1998, 'Parents' perceptions of helpful versus unhelpful types of support in managing the care of preadolescents with chronic conditions', *Archives of Pediatrics & Adolescent Medicine*, 152: 665-671.

Geanellos, R 1998, 'Hermeneutic philosophy. Part I: implications of its use as methodology in interpretative nursing research', *Nursing Inquiry*, (5): 154-163.

Gee, L., Abbott, J., Conway, S. P., Etherington, S. & Webb, A. K. 2000, 'Development of a disease specific health related quality of life measure for adults and adolescents with cystic fibrosis', *Thorax*, 55(11): 946-954.

Gerharz, E. W., Eiser, C. & Woodhouse, C. R. J. 2003, 'Current approaches to assessing the quality of life in children and adolescents', *British Journal of Urology International*, 91: 150-154.

Gibson, C. H. 1999, 'Facilitating critical reflection in mothers of chronically ill children', *Journal of Clinical Nursing*, 8: 305-312.

Gibson, R.L., Burns, J. L., & Ramsey, B. W. 2003, 'Pathophysiology and management of pulmonary infections in cystic fibrosis', *American Journal of Respiratory and Critical Care Medicine*, 168(8): 918-953.

Gilljam, M., Antoniou, M., Shin, J. & Dupuis, A. 2000, 'Pregnancy in cystic fibrosis: fetal and maternal outcome', *Chest*, 118(1): 85.

Gjengedal, E., Rustoen, T, Wahl, A. K. & Hanestad, B. R. 2003, 'Growing up and living with cystic fibrosis: everyday life and encounters with the health care and social services - a qualitative study', *Advances in Nursing Science*, 26(2): 149.



Goldbeck, L., Schmitz, T. G., Henrich, G. & Herschbach, P. 2003, 'Questions on life satisfaction for adolescents and adults with cystic fibrosis: development of a disease-specific questionnaire', *Chest*, 123(1): 42-48.

Goldstone, R. 1998, 'Impaired risk review', *Broker World*, 18(12): 78-80.

Gotz, I. 2003, 'Survival without transplant', *Journal of Cystic Fibrosis*, 2: 55-57.

Graetz, B. W., Shute, R. H. & Sawyer, M. G. 2000, 'An Australian study of adolescents with cystic fibrosis: perceived supportive and nonsupportive behaviours from families and friends and psychological adjustment', *Journal of Adolescent Health*, 26: 64-69.

Grossman, R. 1984, *Phenomenology and Existentialism - An Introduction*, Routledge and Kegan Paul, London.

Guba, E. G. & Lincoln, Y. S. 1989, *Fourth Generation Evaluation*, Sage Publications, Newbury Park, California.

Hallowell, N. 1999, 'Doing the right thing: genetic risk and responsibility', *Sociology of Health & Illness*, 21(5): 597-621.

Hamosh, A., Fitz-Simmons, S. C., Macek, M. Jr, Knowles, M. R., Rosentein, B. J. & Cutting, G. R. 1998, 'Comparison of the clinical manifestations of cystic fibrosis in black and white patients', *Journal of Paediatrics*, 132(2): 255-259.

Hampson, N. 1990, *The Enlightenment: An Evaluation of its Assumptions, Attitudes and Values*, Penguin Books, England.

Harrison, T. R. 1994, *Harrison's Principles of Internal Medicine*, 13<sup>th</sup> edition, eds. Isselbacher, K., Braunwald, E., Wilson, J. D., Martin, J. B., Fauci, A. S. & Kasper, D. L., McGraw-Hill, New York.

Haston, C. K., McKerlie, C., Newbigging, S., Corey, M., Rozmahel, R. & Tsui, L. C. 2002, 'Detection of modifier loci influencing the lung phenotype of cystic fibrosis knockout mice', *Mammalian Genome*, 13(11): 605-613.

Hedgecoe, A. M. 2003, 'Expansion and uncertainty: cystic fibrosis, classification and genetics', *Sociology of Health & Illness*, 25(1): 50-70.

Heidegger, M. 1962, *Being and Time*, trans. J. Macquarrie, and E. Robinson, Harper and Row, New York.

Henderson, L. & Kitzinger, J. 1999, 'The human drama of genetics: "hard" and "soft" media representations of inherited breast cancer', *Sociology of Health & Illness*, 21(5): 560-578.

Hill, C., Thompson, B. & Nutt Williams, E. 1997, 'A guide to conducting consensual research', *Counselling Psychologist*, 25(4): 517-572.

Hillyard, S. 2001, 'Genetically programmed to self-destruct', *The Lancet*, 358: S20.

Hinton, S, Watson, S. & Chesson, R. 2002, 'Information needs of young people with cystic fibrosis', *Paediatric Nursing*, (14) 6: 18-21.

Hodgkinson, R. & Lester, H. 2002, 'Stresses and coping strategies of mothers living with a child with cystic fibrosis: implications for nursing professionals,' *Journal of Advanced Nursing*, 39(4): 377-383.

Husserl, E. 1917, 'Inaugural lecture at Freiburg im Breisgau', in *Husserl: Shorter Works*, trans. R. W. Jordan, eds. P. McCormick, and F. A. Elliston, University of Notre Dame Press, 1981, Indiana, pp. 9-17.

Husserl, E. 1931, *Ideas: General Introduction to Pure Phenomenology*, trans. W.R. Boyce Gibson, Macmillan, New York.

Husserl, E. 1965, *Phenomenology and the Crisis of Philosophy*, trans. Quentin Lauer, Harper Torchbooks, Harper and Row, New York.

Husserl, E. 1999, *Cartesian meditations: an introduction to phenomenology*, trans. Dorion Carins, Kulwer Academic Publishers, The Netherlands.

Hutchinson J. H. 1972, *Practical Paediatric Problems*, Hazell Watson & Viney Ltd, Aylesbury, Bucks. England.

Ievers C. E. Drotar, D. 1996, 'Family and parental functioning in cystic fibrosis', *Developmental and Behavioural Pediatrics*, 17: 48-55.

Ireland, L. & Holloway, I. 1996, 'Qualitative health research with children', *Children & Society*, 10: 155-164.

Iwasa, S., Fujiwara, M., Nagata, M. & Watanabe, T. 2001, 'Three autopsied cases of cystic fibrosis in Japan', *Pathology International*, 51: 467-472.

Jairath, N. 1999, 'Myocardial infarction patients' use of metaphors to share meaning and communicate underlying frames of experience,' *Journal of Advanced Nursing*, 29(2): 283-289.

Jasper, M. 1994, 'Issues in phenomenology for researchers of nursing', *Journal of Advanced Nursing*, 19: 309-314.

Jefferson, M. & Davies, C. 1998, 'Adults with cystic fibrosis', *European Journal of Palliative Care*, 5(4): 107-111.

Jessup, M. 1999, The other side of the bed: how do parents experience the first time hospitalisation of their children following admission for an acute condition?, Honours thesis, University of Tasmania, Australia.

Jessup, M. 2001, Unpublished personal journal.

Jessup, M. 2003, Unpublished personal journal.

Johannesson, M. & Lask, B. 2003, 'Survival against the odds', *Journal of Cystic Fibrosis*, 2: 46-48.

Johnson, M., Long, T., & White, A. 2001, 'Arguments for "British Pluralism" in qualitative health research,' *Journal of Advanced Nursing*, 33(2): 243-249.

Katz, S. 2002, 'When the child's illness is life threatening: impact on the parents', *Pediatric Nursing*, Sep/Oct 2002: 453-463.

Kerr, A. 2000, '(Re)Constructing genetic disease: the clinical continuum between cystic fibrosis and male fertility', *Social Studies of Science*, 30(6): 847-94.

Kieckhefer, G. M. & Trahms, C. M. 2000, 'Supporting development of children with chronic conditions: from compliance toward shared management', *Pediatric Nursing*, 26(4): 354.

King, D. 2004, 'Oh Mickey, you're so fine for genetic research', *The Australian*, March 18, p. 7.

Kleinhenz, M. E. & Stanley, B. F. 2000, 'Decisions in the Management of Adults with Cystic Fibrosis,' *Journal of Clinical Outcome Management*, 7(1): 71-80.

Kliebenstein, M. A. & Broome, M. E. 2000, 'School re-entry for the child with chronic illness: parent and school personnel perceptions', *Pediatric Nursing*, 26(6): 579-585.

Knafl, K. & Deatrick, J. A. 2002, 'The challenge of normalization for families of children with chronic conditions', *Pediatric Nursing*, 28(1): 49-53.

Knafl, K. A. & Gilliss, C. L. 2002, 'Families and chronic illness: A synthesis of current research', *Journal of Family Nursing*, 8(3): 178-198.

- Koch, T. 1998, 'Story telling: is it really research?', *Journal of Advanced Nursing*, 28(6): 1182-1190.
- Krieger, L. 2002, 'Designer Babies,' *The Saturday Mercury* (Hobart), April 13, p. 33.
- Kunk, R. M. 1998, 'Expanding the newborn screen: terrific or troubling?', *The American Journal of Maternal/Clinical Nursing*, 23(5): 266-271.
- Kurland, G. & Orenstein, D. M. 2001, 'Lung transplantation and cystic fibrosis: the psychosocial toll', *Pediatrics*, 107(6): 1419-1421.
- Kyngas, H. 2000, 'Compliance of adolescents with chronic disease', *Journal of Clinical Nursing*, 9: 549-556.
- Lai, H., Corey, M., Fitzsimmons, S., Kosorok, M., & Farrell, P. 1999, 'Comparison of growth status of patients with cystic fibrosis between the United States and Canada', *American Journal of Clinical Nutrition*, 69(3): 531-538.
- Lakoff, G. & Johson, M. 1980, *Metaphors We Live By*, University of Chicago Press, Chicago.
- Lannon Palmer, M. & Boison, L. S. 2002, 'Cystic Fibrosis and the transition to adulthood', *Social Work in Health Care*, 36(1): 45-58.
- Lask, B. 2003, 'Patient-clinician conflict: causes and compromises', *Journal of Cystic Fibrosis*, 2(2003): 42-45.
- Lewis, C.S. 1961, *A Grief Observed*, Faber and Faber Limited, London.
- Lewis, P. A. 1998, 'Inferences for health provision from survival data in cystic fibrosis', *Archives of Disease in Childhood*, 79(4): 297-299.
- Lewis-Gary, M. D. 2001, 'Transitioning to adult health care facilities for young adults with a chronic condition', *Pediatric Nursing*, 27(5): 521-524.

- Lippman, A. & Wilfond, B. S. 1992, 'Twice told tales: stories about genetic disorders', *American Journal of Human Genetics*, 51: 936-937.
- Low, L., King, S. & Wilkie, T. 1998, 'Genetic discrimination in life insurance: empirical evidence from a cross sectional survey of support groups in the United Kingdom', *British Medical Journal*, 317(7173): 1632-1635.
- Lowes, L. & Lyne, P. 2000, 'Chronic sorrow in parents of children with newly diagnosed diabetes: a review of the literature and discussion of the implications for nursing practice', *Journal of Advanced Nursing*, 32(1): 41-48.
- Lowton, K. 2002, 'Can we provide effective palliative care for adults with cystic fibrosis?', *European Journal of Palliative Care*, 9(4): 142-144.
- Lowton, K. 2004, 'Only when I cough? Adults' disclosure of cystic fibrosis', *Qualitative Health Research*, 14(2): 167-186.
- Lowton, K. & Gabe, J. 2003, 'Life on a slippery slope: perceptions of health in adults with cystic fibrosis', *Sociology of Health & Illness*, 25(4): 289-319.
- Macann, C. 1993, *Four Phenomenological Philosophers*, Routledge, London.
- Macready, N. 1997, 'US endorses testing for cystic fibrosis in pregnant women', *British Medical Journal*, 314(7090): 1299.
- Madge, S. & Bryon, M. 2002, 'A model for transition to adult care in cystic fibrosis', *Journal of Pediatric Nursing: Nursing Care of Children and Families*, 17(4): 283-8.
- Madjar, I. 1991, Pain as embodied experience: a phenomenological study of clinically inflicted pain in adult patients, PhD thesis, Massey University, Palmerston North, New Zealand.
- Maggs-Rapport, F. 2000, 'Best research practice: in pursuit of methodological rigour', *Journal of Advanced Nursing*, 35(3): 373-383.

- Mahadeva, R., Webb, K., Westerbeek, C., Carroll, N. R., Dodd, M. E., Bilton, D. & Lomas, D. A. 1998, 'Clinical outcome in relation to care in centres specialising in cystic fibrosis: cross sectional study', *British Medical Journal*, 316: 1771-1775.
- Mandelbaum, D. G. 1973, 'The study of life history: Gandhi', *Current Anthropology*, 14(3): 177-206.
- McDonough, L. 1998, 'Spirit medicine: the body as story', *CF Roundtable*, 6, (Winter), p. 6.
- Melnyk, B. M., Feinstein, N. F., Moldenhouer, Z. & Small, L. 2001, 'Coping in parents of children who are chronically ill: strategies for assessment and intervention', *Pediatric Nursing*, 27(6): 548-558.
- Mendeloff, E. N. 2002, 'The history of pediatric heart and lung transplantation', *Pediatric Transplantation*, 6: 270-279.
- Merullo, R. 2002, 'Of young life and breath', *Philadelphia Inquirer*, April 6.
- Meuleners, L. B., Binns, C. W., Lee, A. H. & Lower, A. 2002, 'Perceptions of the quality of life for the adolescent with a chronic illness by teachers, parents and health professionals: a Delphi study', *Child: Care, Health and Development*, 28(5): 341-349.
- Miles, I. 1986, 'The emergence of sick children's nursing, Part 2', *Nurse Education Today*, 6: 133-138.
- Minicozzi, A. 2000, 'Transition to adult care: another view', *Pediatric Nursing*, 26(4): 411-414.
- Misiak, K. & Sexton, V. S. 1973, *Phenomenological, Existential and Humanistic Psychologies: A Historical Survey*, Grune and Stratton, New York.
- Moore, J. 1988, 'Cystic fibrosis: guiding the family', *The Australian Nurses Journal*, 18(5): 10-11.

Morey, S., Hannon, T., Weng, C. & Gerard, R. 2003, 'Lung transplantation for adults with cystic fibrosis living in Western Australia', *Fifth Australian and New Zealand Cystic Fibrosis Conference Book of Abstracts*, Melbourne, August 21-23, p. 121.

Morton, J., Santos, J., Malouf, M., Plit, M., Horton, M., Wilson, M., Spratt, P. & Glanville, A. 2003, 'Lung transplantation for cystic fibrosis: outcomes of the first one hundred patients at St. Vincent's', *Fifth Australian and New Zealand Cystic Fibrosis Conference Book of Abstracts*, Melbourne, August 21-23, p. 119.

Munhall, P. 1994, *Revisioning Phenomenology: Nursing and Health Science Research*, National League for Nursing Press, New York.

Nelkin, D. & Andrews, L. 1999, 'DNA identification and surveillance creep', *Sociology of Health & Illness*, 21(5): 689-706.

Nespor, J. 1998, 'The meaning of research: kids as subjects and kids as inquirers', *Qualitative Inquiry*, 4(3): 369-388.

Nixon, G. M., Glazner, J. A., Martin, J. M. & Sawyer, S. M. 2002, 'Urinary incontinence in female adolescents with cystic fibrosis', *Pediatrics*, 110(2): e22-30.

Nixon, G. M., Glazner, J. A., Martin, J. M. & Sawyer, S. M. 2003, 'Female sexual health care in cystic fibrosis', *Archives of Disease in Childhood*, 88(3): 265-266.

O'Connor, G. T., Quinton, H.B., Kneeland, T., Kahn, R., Lever, T., Maddock, J., Robichaud, P., Detzer, M. & Swartz, D. R., 2003, 'Median household income and mortality rate in cystic fibrosis', *Pediatrics*, 111(4): 333-339.

Peggy, M., Gerstle, M. & Lapey, A. 2001, 'Adolescents with cystic fibrosis: family reports of adolescent health-related quality of life and forced expiratory volume in one second', *Pediatrics*, 107(5): 70-79.

Petersen, A. R. 1991, *In a Critical Condition: Health and Power Relations in Australia*, Allen & Unwin, Sydney.



Pfeffer, P. E., Pfeffer, J. M. & Hodson, M. E. 2003, 'The psychosocial and psychiatric side of cystic fibrosis in adolescents and adults', *Journal of Cystic Fibrosis*, 2(2): 61-68.

Polnay, J. C., Davidge, A., Chin Lyn, U. & Smyth, A. R. 2002, 'Parental attitudes: antenatal diagnosis of cystic fibrosis', *Archives of Disease in Childhood*, 87(4): 284-286.

Puotiniemi T, Kyngas, H. & Nikkonen, M. 2001, 'Factors associated with the coping of parents with a child in psychiatric in patient care', *International Journal of Nursing Practice*, 7: 298-303.

Quittner, A. L., Espelage, D. L., Opiari, L. C., Carter, B., Eid, N. & Eigen, H. 1998, 'Role strain in couples with and without a child with a chronic illness: associations with marital satisfaction, intimacy, and daily mood', *Health Psychology*, 17(2): 112-124.

Rask, K., Kaunonen, M. & Paunonen-Ilmonen. 2002, 'Adolescent coping with grief after the death of a loved one', *International Journal of Nursing Practice*, 8: 137-142.

Raskin, S., Phillips III, J. A., Krishnamani, M. R. S. & Vnencak-Jones, C. 1997, 'Cystic fibrosis in the Brazilian population: DF508 mutation and KM-19/XV-2C haplotype distribution', *Human Biology*, 69(4): 499-508.

Raymond, N. C., Chang, P. N., Crow, S. J., Mitchell, J. E. Dieperink, B. S., Beck, M. M., Crosby, R. D., Clawson, C. C. & Warwick, W. J. 2000, 'Eating disorders in patients with cystic fibrosis', *Journal of Adolescence*, 23: 359-363.

Robinson, P. 2001, 'Cystic fibrosis,' *Thorax*, 56: 237-241.

Robinson, W. M., Ravilly, S., Berde, C. & Wohl, M. E. 1997, 'End-of-life care in cystic fibrosis', *Pediatrics*, 100(2): 205-209.

Rosenfeld, M., Davis, R., FitzSimmons, S., Pepe, M. & Ramsey, B. 1997, 'Gender gap in cystic fibrosis mortality', *American Journal of Epidemiology*, 145(9): 794-803.

Rozmovits, L. & Ziebland, S. 2004, 'Expressions of Loss of Adulthood in the Narratives of People with Colorectal Cancer', *Qualitative Health Research*, 14(2): 187-203.

Sanders, M. R., Turner, K. M., Wall, C. R., Waugh, L. M. & Tully, L. A. 1997, 'Mealtime behaviour and parent-child interaction: a comparison of children with cystic fibrosis, children with feeding problems, and nonclinic controls', *Journal of Pediatric Psychiatry*, 22: 881-900.

Sartain, S., Clarke, C. & Heyman, R. 2000, 'Hearing the voices of children with chronic illness', *Journal Of Advanced Nursing*, 32(4): 913-921.

Sawin, K. J., Bellin, M. H., Roux, G., Buran, C., Brei, T. J. & Fastenau, P. S. 2003, 'The experience of parenting an adolescent with spina bifida', *Rehabilitation Nursing*, 28(6): 173-185.

Sawyer, S. 1996, 'Reproductive and sexual health in adolescents with cystic fibrosis', *British Medical Journal*, 313(7065): 1095-1096.

Sawyer, S. M., Tully, M. A., Dovey, M. E. & Colin, A. A. 1998, 'Reproductive health in males with cystic fibrosis: knowledge, attitudes, and experiences of patients and parents', *Pediatric Pulmonology*, 27(4): 293.

Sawyer, S. M., Tully, M-A. M. & Colin, A. A. 2001, 'Reproductive and sexual health in males with cystic fibrosis: a case for health professional education and training,' *Journal of Adolescent Health*, 28(1): 36-40.

Scal, P., Evans, T., Blozis, S., Okinow, N. & Blum, R. 1999, 'Trends in transition from pediatric to adult health care services for young adults with chronic conditions', *Journal of Adolescent Health*, 24(4): 259-264.

Seeley, R. D., Stephens, T. D. & Tate, P. 1995, *Anatomy & Physiology, third edition*, Mosby, St. Louis, Missouri.

- Sellman, M. 2002, 'Kiss on the Salty Forehead', *BellaOnline*, [Online, accessed October 14, 2002] <http://www.bellaonline.org/ArticlesP/art4626.asp>.
- Serrano-Ikkos, E. & Lask, B. 2003, 'The psychosocial correlates of transplant survival', *Journal of Cystic Fibrosis*, 2: 49-54.
- Serrano-Ikkos, E., Lask, B., Whitehead, B, Rees, P. & Graham, P. 1999, 'Heart or heart-lung transplantation: Psychosocial outcome', *Pediatric Transplantation*, 3: 301-308.
- Silva, F. G. 2002, 'Ethics of the new biology and genetic medicine (molecular ethics): brief (re)view from the USA', *Pathology International*, 52: 555-562.
- Sluga, H. 1995, *Heidegger's Crisis: Philosophy and Politics in Nazi Germany*, Harvard University Press, Massachusetts.
- Smith, J. 1998, "'Qualitative Research in Health and Social Care": conference organized by The Institute of Health and Community Studies, Bournemouth University,' *Journal of Advanced Nursing*, 28(4): 925-929.
- Solomon, C. R. & Breton, J. J. 1999, 'Early warning signals in relationships between parents and young children with cystic fibrosis', *Children's Health Care*, 28(3): 221-240.
- Spiegelberg, H. 1982, *The Phenomenological Movement: A Historical Introduction*, 3<sup>rd</sup> edition, Martinus-Nijhoff, Boston.
- Staab, D., Wenninger, K., Gebert, N. & Rupprath, K. 1998, 'Quality of life in patients with cystic fibrosis and their parents: what is important besides disease severity?', *Thorax*, 53(9): 727-731.
- Staff, A. C. 2001, 'An introduction to gene therapy and its potential prenatal use,' *Acta Obstetricia et Gynecologica Scandinavica*, 80: 485-491.

Stanghelle, J. K., Koss, J. O., Bjortuft, O. & Geiran, O. 2000, 'Marathon with cystic fibrosis and bilateral lung transplant', *Scandinavian Journal of Medicine & Science in Sports*, 10: 42-46.

Steiner, G. 1978, *Heidegger*, Fontana, London.

Stevens, R. F. & Meyer, S. 2002, 'Fanconi and Glanzmann: the men and their works', *British Journal of Haematology*, (119): 901-904.

Stewart, D. & Mickunas, A. 1974, *Exploring Phenomenology: A Guide to the Field and its Literature*, American Library Association, USA.

Stewart, K. C. & Patterson, G. A. 2001, 'Current Trends in Lung Transplantation', *American Journal of Transplantation*, 1: 204-210.

*Still Breathing*, screened SBS TV, August 25, 2003.

Stockdale, A. 1999, 'Waiting for the cure: mapping the social relations of human gene therapy research', *Sociology of Health & Illness*, 21(5): 579-596.

Stuhrmann, M. & Dork, T. 2000, 'CFTR gene mutations and male infertility', *Andrologia*, 32: 71-83.

Tanackovic, G., Barisic, I., Gjergja-Matejic, R., Hecimovic, S. & Pavelic, J. 2000, 'The incidence of cystic fibrosis (CF) mutations among patients from Croatia', *Clinical Genetics*, 58: 333-335.

Thomlinson, E. H. 2002, 'The lived experience of families who are failing to thrive', *Journal of Advanced Nursing*, 39(6): 537-545.

Thompson, R. G. 1998, 'Illness specific patterns of psychological adjustment and cognitive adaptational processes in children with cystic fibrosis and sickle cell disease', *Journal of Clinical Psychology*, 54(1): 121-128.

Tippl, H. A. 1995, 'Significant relationships: nurses caring for adolescents with cystic fibrosis', *Contemporary Nurse*, 4: 123-128.

Tropauer, A., Neal Franz, M. & Dilgard, V. W. 1970, 'Psychological aspects of the care of children with cystic fibrosis', *American Journal of Diseases of Children*, 119: 424-432.

Truby, H. P. & Paxton, S. J. 2001, 'Body image and dieting behaviour in cystic fibrosis', *Pediatrics*, 107: e92-98.

Turk, J. 1964, 'Impact of cystic fibrosis of family functioning', *Pediatrics*, July: 67-71.

Turner, J. 1984, 'A parent's perspective', *Nursing*, 159(18): 23-25.

Tzetis, M., Kanavakis, E., Antoniadis, T., Doudounakis, S., Adam, G. & Kattamis, C. 1997, 'Characterization of more than 85% of cystic fibrosis alleles in the Greek population, including five novel mutations', *Human Genetics*, 99(1): 121-125.

United Kingdom National Steering Committee 2002, 'Information sheet on antenatal and neonatal screening for cystic fibrosis', [Online, accessed 16 October, 2002] <http://www.nsc.nhs.uk>.

Van Manen, M. 1990, *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*, State University of New York Press, Albany, New York.

Van Manen, M. 1994, 'Modalities of Body Experience in Illness and Health', presented as a keynote at the Qualitative Research in healthcare Conference, Pennsylvania State University, Hershey, PA. June 9-13, 1994, *Qualitative Health Research*, 8(1): 7-24.

Van Manen, M. 1996a, 'From meaning to method', *Qualitative Health Research: An International, Interdisciplinary Journal*, 7(3): 345-369.

- Van Manen, M. 1996b, 'Phenomenological Pedagogy and the Question of Meaning', in *Phenomenology and Educational Discourse*, ed. Donald Vandenberg, Heinemann Higher and Further Education, Durban, South Africa, pp. 39-64.
- Van Manen, M. 1997, *Researching Lived Experience, Preface to the Second (Canadian) Edition*, Althouse Press, Faculty of Education, University of Western Ontario, Canada.
- Van Manen, M. 1999, 'Foreword,' in *Nursing and the Experience of Illness: Phenomenology in practice*, eds. Irena Madjar & Jo Ann Walton, Allen & Unwin, Australia, pp. v-viii.
- Van Manen, M. 2002, 'Modalities of body experience in illness and health', *Qualitative Health Research: An International, Interdisciplinary Journal*, 8(1): 7-24.
- Varni, J. W., Seid, M. & Rode, C. A. 1999, 'The PedsQL: measurement model for the pediatric quality of life inventory', *Medical Care*, 37(2): 126-139.
- Vezeau, T. 1994, 'Narrative in nursing practice and education' in eds. P.Chinn & J.Watson, *Art and Aesthetic in Nursing*, National League for Nursing Press, New York, pp. 163-188.
- Viner, R. 2000, 'Effective transition from paediatric to adult services', *Hospital Medicine*, 61(5): 341-343.
- Vittone, S. 2001, 'Lung transplantation for cystic fibrosis: additional considerations', *Pediatric Nursing*, 27(1): 90-92.
- Von Herrmann, F-W. 1993, 'Being and time and the basic problems of phenomenology', in *Reading Heidegger: Commemorations*, ed. John Sallis, Indiana Press, Bloomington and Indianapolis, pp. 118-135.
- Wade, N. 1997, 'Testing genes to save a life without costing you a job', *The New York Times*, September 14, p. 5.

Waksler, F. C. 1986, 'Studying children: phenomenological insights', *Human Studies*, 9: 71-82.

Wald, N. J., George, L. M. & Wald, N. M. 1993, 'Couple screening for cystic fibrosis', *The Lancet*, 342: 1308.

Walling, A. D. 2002, 'Pregnancy in women with cystic fibrosis', *American Family Physician*, 65(12): 2583.

Walsh, K. 1996, 'Philosophical hermeneutics and the project of Hans Georg Gadamer: implications for nursing research', *Nursing Inquiry*, (3): 231-237.

Walters, S. 2002, 'National health services for patients with cystic fibrosis: the good, the bad and the ugly', *Journal of the Royal Society of Medicine*, 95 (Supplement: Current Clinical Issues in Cystic Fibrosis), p. 32-40.

Westwood, A. T. R., Henley, L. D. & Willcox, P. 1999, 'Transition from paediatric to adult care for persons with cystic fibrosis: patient and parent perspectives', *Journal of Paediatrics and Child Health*, 35(5): 442-445.

Whyte, D. 1989, 'The experience of families caring for a child with cystic fibrosis - a nursing response', PhD thesis, University of Edinburgh.

Wideman, E. 2002, 'Communicating a diagnosis of cystic fibrosis to an adult: what physicians need to know', *Behavioral Medicine*, 28: 45-52.

Wideman, E. 2003, 'Knowledge, interests and educational needs of adults diagnosed with cystic fibrosis after age 18', *Journal of Cystic Fibrosis*, 2(2): 97-104.

Wiklund, L., Lisbet, L. & Lindstrom, U. A. 2002, 'Hermeneutics and narration: a way to deal with qualitative data', *Nursing Inquiry*, 9(2): 114-125.

Wilde, M. H. 2003, 'Embodied knowledge in chronic illness and injury', *Nursing Inquiry*, 10 (3): 170-176.

Willis, E. Miller, R. & Wyn, J. 2001, 'Gendered embodiment and survival for young people with cystic fibrosis', *Social Science and Medicine*, 53(9): 1163-1174.

Wood, D. 1993, 'Reiterating the temporal: toward a rethinking of Heidegger on time', in *Reading Heidegger: Commemorations*, ed. John Sallis, Indiana Press, Bloomington and Indianapolis, pp. 136-159.

World Health Organization/International Cystic Fibrosis (Mucoviscidosis) Association 1997, 'Implementation of cystic fibrosis services in developing countries: memorandum from a Joint WHO/ICF (M) A. meeting', *Bulletin of the World Health Organization*, 75(1): 1-10.

Wurzbach, M. E. 1999, 'The moral metaphors of nursing', *Journal of Advanced Nursing*, 30(1): 94-99.

Wyss, J. *The Swiss Family Robinson*, Dean & Son Limited, London.

Yamashiro, Y., Shimizu, T., Oguchi, S., Shioya, T., Nagata, S. & Ohtsuk, Y. 1997, 'The estimated incidence of cystic fibrosis in Japan', *Journal of Pediatric Gastroenterology & Nutrition*, 24(5): 544-547.

Yankaskas, J. R., Mallory, G. B. & the Consensus Committee 1998, 'Lung transplantation in cystic fibrosis: consensus conference statement', *Chest*, 1: 217-226.

Yoshimura, K., Wakazono, Y., Iizuka, S., Morokawa, N., Tada, H. & Eto, Y. 1999, 'A Japanese patient homozygous for the H1085R mutation in the CFTR gene presents with a severe form of cystic fibrosis', *Clinical Genetics*, 56: 173-175.

Zhang, S-Y, 1993, 'Heidegger and Toaism', in *Reading Heidegger: Commemorations*, ed. John Sallis, Indiana Press, Bloomington and Indianapolis, pp. 307-320.

Zoritch, B., Eiser, C., Hiller, E. J. & Taylor, C. 1996, 'Cystic fibrosis and school: the teachers' viewpoint', *Ambulatory Child Health*, (1): 302-310.